HIV SENSITIVE SOCIAL PROTECTION
A FOUR STATE UTILISATION STUDY

TISS-UNDP Collaboration
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A FOUR STATE UTILIZATION STUDY

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HIV Sensitive Social Protection: A four state utilization study

This report describes selected social protection schemes in India for under-privileged and vulnerable populations in general and their relevance to people living with HIV (PLHIV) in particular. It assesses the utilisation of the schemes by PLHIV and highlights the experiences of users and non-users among the PLHIV in accessing the schemes. Facilitating factors and barriers to access are identified.

Vimla Nadkarni, Sheetal Goel, Swati Pongurlekar

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Manufactured in India
Foreword

It is estimated that 2.24 million people are living with HIV in India today. Evidence shows that People Living with HIV (PLHIV) and their households adopt a range of strategies to cope with chronic illness, the loss of an income earner and to cover medical treatment. Coping mechanisms include reduced consumption on essential items including food, borrowing from moneylenders and extended hours of work by women and children to care for the sick and make up for the loss of an income earner. The impact is worst in households headed by HIV widows. The severe and wide-ranging socio-economic impact on PLHIV and their households is further aggravated by stigma and discrimination and slows down the uptake of HIV prevention and treatment services.

Given the increasing importance for expanding universal access and for mitigating the impact on people and families affected by HIV, social protection has emerged as one of the critical strategies for an effective AIDS response. Social protection is an important policy tool for tackling exclusion, inequality and poverty.

Building on the learnings of the 2006 UNDP NACO NCAER study on the Social and Economic Impact of HIV, UNDP has been supporting national efforts towards HIV mainstreaming. It has been working closely with networks of positive people, civil society organizations and the National AIDS Control Organization and State Societies to advocate for HIV sensitive as well as HIV specific schemes for PLHIV. States in India are moving at different paces in designing and implementing social protection options for PLHIV.

This report ‘HIV Sensitive Social Protection: A Four State Utilization Study’ has analysed the efforts, opportunities and challenges experienced by PLHIV in the utilization of schemes pertaining to food, transportation, pensions, housing, education and employment generation in the states of Gujarat, Orissa, Rajasthan and Tamil Nadu.

The study stresses that while the policy framework for social protection is important, it is of equal importance to have a vigilant and active community of PLHIV to ensure that the HIV-sensitive schemes are accessed and utilised fully.

The study provides evidence that the successes are a result of combined efforts of the positive people’s networks, NGOs, government departments, and the State AIDS Control Societies (SACS). Each of these stakeholders has a unique strength and when working together synergistically have made access to social protection a reality for PLHIV. Committed policy makers, sensitive administrators and active networks can ensure a comprehensive social protection package for PLHIV.

To ensure that PLHIV are better able to cope with multiple vulnerabilities, the social protection agenda needs to be inclusive and as indicated by the present study is easily achievable.

Caitlin Wiesen
Country Director
UNDP India

Patrice Coeur-Bizot
UN Resident Coordinator &
UNDP Resident Representative India
Message

Social protection is a relatively new and evolving area. Certainly, it owes much of its recently-gained attention to the HIV epidemic, which has forced a re-think on ‘what works’ in support of protecting and promoting the rights of PLHIV and marginalized groups.

The United Nations Development Programme India has been a trusted partner of NACO through the National AIDS Control Programme. The current phase of NACP 3 has been instrumental in laying the very basis of our evolving thought processes around social protection and strategic partnerships for mainstreaming of HIV.

The study “HIV Sensitive Social Protection: A four state utilization study” aims at describing select social protection schemes for under-privileged and vulnerable populations in general and their relevance to PLHIV in particular. It assesses the utilisation of the schemes by PLHIVs and highlights the experiences of users and nonusers among the PLHIV in accessing the schemes. The study calls for ensuring existing social protection mechanisms to include people living with HIV, populations at higher risk, vulnerable populations and households in order that they can access the services and entitlements that they need. It also recommends opening up well-established social security approaches to people living with HIV.

As NACO charts the course for the next phase of NACP, we recognize that people living with HIV, marginalized groups like FSW, MSM, TG and households affected by HIV need to be addressed in all national social protection strategies and have access to essential care and support. It can also help to ensure that efforts to expand universal access to HIV prevention, treatment, care and support will reach the most difficult to reach bearing in mind the constraining and enabling factors that have been articulated in the study.

This study attempts to get a better understanding on such issues. I would like to acknowledge the contribution of UNDP and TISS in building and strengthening the evidence base for social protection in India.

Aradhana Johri, IAS
Additional Secretary
NACO
Acknowledgements

This study is an appraisal of the utilisation of social protection schemes by People living with HIV (PLHIVs). The key objective of the study is to identify factors that facilitate and constrain the optimal use of benefits under schemes by the PLHIV. The states (Gujarat, Orissa, Rajasthan and Tamil Nadu) were selected as they represent different levels of prevalence, differing stages of putting together a social protection framework and varying magnitudes of use of the schemes. A rapid appraisal of utilisation of the social protection schemes relevant for people infected and affected by HIV and AIDS was carried out in the months of August-September, 2010 by Cell for AIDS Research Action and Training (CARAT), Centre for Health and Mental Health, School of Social Work, TISS. Data were gathered from key informants among the people living with HIV, both users and non-users of the schemes, with service-providers and key decision-makers within the government and non-government organisations.

The data shows insightful trends in the use of the various schemes, some mainstreamed with the general populace while some specifically marked for use by the PLHIVs. There seem to be advantages of both mainstreaming and targeted schemes, keeping in view the issues of confidentiality and stigma that complicate the utilisation of the schemes by PLHIV.

The team is grateful to all the participants in this study. Yes, participants... because they are the critical mass of people who have given so much of their time and commitment, frankly discussing their concerns and therefore, own the data and the report. Thanks are also due to all the officials of the government and non-government organisations who participated in this study with enthusiasm and sincerity.

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Executive Summary

Introduction
Evidence indicates that HIV households struggle and cope with risks by reducing consumption on essential items including food, borrowing from moneylenders (often at very high interest rates), extended hours of work by women and children or a complete dependence on other family members or NGOs. The situation of vulnerability is also accentuated for a woman irrespective of her being a widow a sex worker, partner of injecting drug user or living with HIV herself. According to UNDP 2009 ‘HIV and women’s inheritance and property rights’ study, women who are denied their right to inheritance and property are at heightened risk to sexual exploitation, violence and HIV.

The social and economic impact is also more pronounced on women and households headed by HIV widows -whether they are themselves living with HIV or not. Extending social protection to PLHIVs through the State led poverty alleviation programmes, to cope with the risks is receiving attention both at the global and national level. National AIDS Control Organisation (NACO), with technical support from UNDP, has forged multi-sectoral collaborations with government ministries and has advocated for amendment or adaptation of policies and schemes for social protection of people living with and affected by HIV.

Against this backdrop, this study presents a situational analysis of the experiences in the uptake of social protection schemes by PLHIVs. The main objective of the study was to identify different social protection schemes of the government relevant to PLHIVs and to identify the facilitating and constraining factors in accessing these schemes by PLHIVs.

The findings of this study also showcase some of the successful strategies in implementing the social protection schemes for PLHIVs and can be used for cross learning between States across India to initiate and upscale their efforts.

Methodology
This is a qualitative research study carried out in four select states – Gujarat, Orissa, Rajasthan and Tamil Nadu. The purpose of selecting these States is to represent states with different HIV prevalence rates and to ensure a mix of states with different levels of mainstreaming activities initiated by UNDP and the respective State AIDS Control Societies (SACS). The study is based on an extensive analysis of secondary data on utilisation of schemes. In order to sharpen the secondary analysis, attempt was also made to bring in voices of the people that included representatives from SACS, positive people’s networks (PPNs) and NGOs. FGD and in depth interviews were conducted A total of 147 individuals participated in this process.

Findings
The study found an evidence of more than 25 different types of schemes (inclusive of state specific and central schemes) that are relevant to PLHIVs that includes travel concession, pension, food and nutrition, wage/ self employment, health, education of children, housing, crisis assistance and legal aid.
The mainstreaming initiatives of the respective SACS in collaboration with the positive people’s networks, UNDP and NGOs has helped PLHIVs to draw benefits from the different central and state government sponsored social protection schemes. While there are similarities in the type of mainstream schemes being tapped, there exist state level variations in the access and amount of benefit accrued through the different social protection schemes.

Gujarat
Gujarat had focused on schemes like Tabibi Sahay (a monthly benefit of ` 500 for nutritional support), reimbursement of travel to Anti-retroviral treatment (ART) centres through the Jatan Project of the Gujarat State Government, widow pension scheme (a monthly amount of ` 500), Palak Mata Pita Scheme for AIDS orphans, Antyodaya Anna Yojana (food subsidy) and livelihood schemes through Mahatama Gandhi National Rural Employment Guarantee Act (MGNREGA) and self-help groups for PLHIVs within the State.

Gujarat State AIDS Control Society (GSACS) had promoted empowerment of Gujarat State Network for Positive People (GSNP+) by providing employment to PLHIVs associated with the network, through the Jeevandeep project in each district. This project trained their staff to enable uptake of different social protection schemes by PLHIVs. Addressing procedural issues related to the aforementioned schemes continued to remain on the work list of GSNP+ and GSACS so that more number of PLHIVs can avail the schemes.

One of the interesting features in Gujarat was the presence of relatively affluent PLHIVs who hailed from a diamond and textile industry of Surat as compared to lesser well-off PLHIVs in the State. While the former’s priority needs included free second line ART drugs and reservation in higher education for children, the latter sought support for nutrition, transport concessions, livelihoods etc. The district level network at Ahmedabad had created livelihood opportunities for many by tapping resources through the huge Gujarati diaspora.

Orissa
In Orissa, the most accessed scheme was the pension scheme (` 200 per month) under the Madhu Babu Pension Scheme. Another scheme utilised by PLHIVs was the Mo Kudiya housing scheme, which provided ` 35000 for construction of house to PLHIV’s with BPL status and having land. PLHIVs availed of travel reimbursements through the Indian Red Cross Society (IRCS) although the disbursement channels varied across districts (the minimum amount received here was ` 70 and maximum was ` 200 if travelling from different district). The other schemes accessed were Antyodaya Anna Yojana and National Family Benefit scheme (NFBS) (` 10,000 is given to the family on the death of a breadwinner).

Madhu Babu Pension scheme emerged as the most popular schemes in Orissa, but procedural issues such as delays between applying and receipt of benefit remained to be addressed. There is a demand from different stakeholders to upscale the pension amount to Rs. 500 from the current Rs. 200. Although PLHIVs had benefitted from other useful schemes like NFBS, there was no uniform and collective effort to avail the benefits of this scheme across all districts. This could be because of the relatively new network of people living with HIV.
Rajasthan

Rajasthan Network for Positive People (RNP+) had placed access to central/ state government social protection schemes on their care and support agenda. This had facilitated their focus on social protection schemes like widow pension, Palanhar yojana, Antyodaya Anna Yojana (AAY), travel concession (bus pass) for ART treatment and BPL card to receive free medical treatment under the Mukhya Mantri Jeevan Raksha Kosh (MMJRK) scheme.

RNP+ had received support for RSACS and other development agencies such as UNDP, World Vision, UNICEF, etc, and other local NGOs to plan and improve access of PLHIVs to these social protection schemes.

The joint advocacy (by RNP+ and RSACS) for special provisions within mainstream schemes had been successful in different ways. However, the operations were at a nascent stage where many PLHIVs associated with the district level networks (DLNs) were beginning to apply for the schemes and facing procedural challenges. Those who are able to navigate through these challenges received the benefits of the schemes.

Tamil Nadu

Widow pension was the most commonly used scheme among women in Tamil Nadu (a monthly benefit of Rs. 500 per month). Many had availed schemes like MGNREGA and Indira Awas Yojana, but, this was facilitated by the BPL status of the HIV household and not necessarily the HIV status. Other livelihood options came through loans provided by Tamil Nadu Adi Dravida Housing Development Corporation (THADCO) for self employment like goat / cow rearing. Railway travel concession, a hitherto popular scheme saw a reduced uptake after link ART centres opened up in each district in Tamil Nadu as buses were preferred for short distance travel. The legal aid clinics housed in the ICTC centres across 16 districts of Tamil Nadu made a significant contribution in guiding women and men regarding social protection schemes and also helped applicants in procuring the ration card or with other legal documents like affidavits, etc.

The state health insurance scheme known as ‘Kalaignar Kapitu thittam’, recently introduced for PLHIVs enabled them to receive free investigation facilities in government hospitals. STAR health insurance was promoted by the INP plus and was also availed by many. Network of women living with HIV were successful in working around the middlemen and corruption that sometimes proved to constrain access to services.

Each state seemed to have success stories based on experiences of implementation of schemes that others could learn from or consider replicating in their local context. The successful strategies that promoted the uptake of social protection schemes among PLHIVs included the special provisions for PLHIVs within mainstream social protection schemes, routing of schemes through the ART centre or through the legal aid clinic (in the case of Tamil Nadu) and enabling empowerment of positive people’s networks to access social protection schemes.

Positive people’s networks, NGOs and the SACS are the force behind the uptake of social protection schemes by PLHIVs. Each of these stakeholders has a comparative advantage and their synergies have made access to social protection schemes a reality for PLHIVs. Interestingly, different states were able to capitalise on different mainstream schemes thereby indicating a
A complex interplay of several stakeholders from the State Ministries/ Departments, the District Administration and the Panchayati Raj institutions. The dynamic role of individuals/ officials occupying these offices either facilitated or constrained the uptake of schemes. Sensitive, cooperative and proactive individuals significantly contributed in the form of approval for special provisions in mainstream schemes and enabled easy disbursal of benefits.

The assertive stand taken by users, networks and NGOs (either individually or collectively) against an indifferent service delivery system, discriminatory acts of service providers and issues relating to corruption had been significant in the realisation of rights and entitlements as per the social protection schemes. PLHIVs who attempted to apply for the different social protection schemes confronted with procedural issues like restrictive eligibility criteria, cumbersome application procedures, delays in receipt of benefit and opportunity costs which either constrained them from receiving the benefits or restricted their participation altogether. Governance related issues like corruption, bribes, leakages and lack of quality in services further posed as barriers in the uptake of social protection schemes.

Awareness about social protection schemes had not necessarily led to their access because of its dependency on several other factors. However, awareness about schemes along with details about the application procedures was a pre-condition to initiate the right steps in this direction.

Challenges in form of disclosure and confidentiality issues, stigma and discrimination and gender constraints had also come in the way of accessing the schemes.

Many social protection schemes were targeted to BPL households. This constrained many HIV households who were poor but not necessarily in possession of the BPL card. Special provisions or a conditional BPL status had helped PLHIVs access such schemes. HIV households facing multiple deprivations were likely to be pushed below poverty line.

**Conclusion**

There exist state wide variations in the availability, access and amount of benefit accrued from the different social protection schemes relevant to PLHIVs. Given this situation, there is a need for policy intervention at the national level to universalise relevant schemes based on priority needs of PLHIVs and to bring a level of parity in the benefits received by PLHIVs across the states.

Based on risks faced by HIV households and the study participants’ perspectives on social protection needs, this study suggests social protection for HIV households through a package of schemes that will reduce the risks and improve coping mechanisms of such households.

*Basic package* for all HIV households could cover health related schemes (especially health insurance) and food and nutrition schemes. These two categories of schemes are likely to reduce the household burden of medical expenses and also ensure a minimum intake of food. HIV households that are comparatively better resourced may find themselves prevented from sliding down further. A *basic plus package* is recommended for HIV households (especially women, youth, children, destitute men, socially marginalised groups like sex workers,
transgenders, MSMs and IDUs) facing multiple deprivations who would need additional social assistance. This could come in the form of cash transfers (both conditional and unconditional) to ensure a basic survival, livelihood options (to make them more self-reliant and reduce dependency on cash transfers), insurance schemes and housing options (especially for those facing desertion).

Routing of schemes through the ICTC/ART/ link ART centres or legal aid clinics (in case Tamil Nadu), such that they become a one-stop-shop for applying and receiving of schemes is suggested as a way to reduce the procedural barriers and issues related to disclosure and discrimination. Additionally sensitisation of government personnel at all service delivery points may also help to reduce the stigma and discrimination issues.

There is also a need to create greater awareness among PLHIVs about the different social protection schemes through use of mass awareness and interpersonal communication strategies. PLHIVs also need to be encouraged to take assertive stands against corrupt and indifferent service delivery systems to make them more accountable.

Advocating with the mainstream government ministries to review the eligibility criteria to make them more inclusive and have regular consultations to address grievances faced by users of the schemes may further facilitate access to social protection schemes.

Maintaining data on utilisation of the schemes by PLHIVs will be crucial to understand the uptake of social protection schemes by PLHIVs.

Most at risk populations (MARPs) like the MSMs, TGs, FSWs and IDUs are likely to experience greater challenges in the access of social protection schemes because of their marginalised status. The MARPs were not adequately represented from all states in this study and therefore further research is required to understand the specific challenges faced by them in accessing social protection schemes and, to inform suitable interventions.

The study was conducted with PLHIVs registered with the different state/district level networks and they had been able to use the networking abilities of their association with the network to gain access to schemes. A study with PLHIVs not registered with the networks is desirable to understand the challenges faced them accessing the schemes. Quantitative studies that entail household surveys will further help to understand the impact of the social protection schemes on poverty alleviation of HIV households.
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# Abbreviations and Acronyms

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<tr>
<td>AAY</td>
<td>Antyodaya Anna Yojana</td>
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<tr>
<td>AIDS</td>
<td>Acquired Immuno Deficiency syndrome</td>
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<td>ANC</td>
<td>Ante Natal Care</td>
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<td>ANM</td>
<td>Auxiliary Nurse Midwife</td>
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<td>APL</td>
<td>Above Poverty Line</td>
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<td>ART</td>
<td>Anti Retroviral Therapy</td>
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<td>BDO</td>
<td>Block Development Officer</td>
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<td>BNP+</td>
<td>Bhubaneshwar Network for Positive People</td>
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<td>BPL</td>
<td>Below Poverty Line</td>
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<td>CD4</td>
<td>Cluster of Differentiation 4</td>
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<tr>
<td>CHC</td>
<td>Community Health Centre</td>
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<td>CLHIV</td>
<td>Child Living with HIV</td>
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<tr>
<td>CST</td>
<td>Care, support and treatment</td>
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<tr>
<td>DAPCU</td>
<td>District AIDS/ HIV Prevention and Control Unit</td>
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<tr>
<td>DIC</td>
<td>Drop In Centre</td>
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<td>DLN</td>
<td>District Level Network</td>
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<td>DPO</td>
<td>District Programme Officer</td>
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<td>DRDA</td>
<td>District Rural Development Agency</td>
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<td>FGD</td>
<td>Focus Group Discussion</td>
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<td>FPS</td>
<td>Fair Price Shops</td>
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<td>FSW</td>
<td>Female Sex Worker</td>
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<td>GSACS</td>
<td>Gujarat State AIDS Control Society</td>
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<td>GSNP+</td>
<td>Gujarat State Network for Positive People</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>ICDS</td>
<td>Integrated Child Development Services</td>
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<td>ICTC</td>
<td>Integrated Counselling and Testing Centre</td>
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<td>IDU</td>
<td>Injecting Drug User</td>
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<td>IEC</td>
<td>Information Education Communication</td>
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<td>INP+</td>
<td>Indian Network for Positive People</td>
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<tr>
<td>IPD</td>
<td>In Patient Department</td>
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<td>IRCS</td>
<td>Indian Red Cross Society</td>
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<td>JSY</td>
<td>Janani Suraksha Yojana</td>
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<td>KKT</td>
<td>Kalaignar Kapitu Thittam</td>
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<td>KNP+</td>
<td>Kalinga Network for Positive People</td>
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<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>LAC</td>
<td>Link ART Centre</td>
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<td>MARPs</td>
<td>Most At Risk Populations</td>
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<tr>
<td>MBPS</td>
<td>Madhu Babu Pension Scheme</td>
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<td>MDMS</td>
<td>Mid Day Meal Scheme</td>
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<tr>
<td>MGNREGA</td>
<td>Mahatma Gandhi National Rural Employment Guarantee Act</td>
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<tr>
<td>MMJRK</td>
<td>Mukhya Mantri Jeevan Raksha Kosh</td>
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<tr>
<td>MoRD</td>
<td>Ministry of Rural Development</td>
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<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
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<tr>
<td>NACO</td>
<td>National AIDS Control Society</td>
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<tr>
<td>NACP</td>
<td>National AIDS Control Programme</td>
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<td>NFBS</td>
<td>National Family Benefit Scheme</td>
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<td>NGO</td>
<td>Non Government Organisation</td>
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<td>NOAPS</td>
<td>National Old Age Pension Scheme</td>
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<td>NRHM</td>
<td>National Rural Health Mission</td>
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<td>NSAP</td>
<td>National Social Assistance Programme</td>
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<tr>
<td>OIs</td>
<td>Opportunistic Infections</td>
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<tr>
<td>OPD</td>
<td>Out Patient Department</td>
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<tr>
<td>OSACS</td>
<td>Orissa State AIDS Control Society</td>
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<tr>
<td>OVC</td>
<td>Orphans and Vulnerable Children</td>
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<tr>
<td>PEP</td>
<td>Post Exposure Prophylaxis</td>
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<tr>
<td>PHC</td>
<td>Primary Health Centre</td>
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<tr>
<td>PLHIV</td>
<td>Person Living with HIV</td>
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<td>PPN</td>
<td>Positive People’s Network</td>
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<tr>
<td>PPTCT</td>
<td>Prevention of Parent To Child Transmission</td>
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<tr>
<td>PRIs</td>
<td>Panchayati Raj Institutions</td>
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<tr>
<td>PSI</td>
<td>Population Services International</td>
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<tr>
<td>PWN</td>
<td>Positive Women’s Network</td>
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<tr>
<td>RNP+</td>
<td>Rajasthan State Network for Positive People</td>
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<tr>
<td>RSACS</td>
<td>Rajasthan State AIDS Control Society</td>
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<tr>
<td>SACS</td>
<td>State AIDS Control Society</td>
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<tr>
<td>SGSY</td>
<td>Swarnajayanti Gram SwarojgarYojana</td>
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<tr>
<td>SHGs</td>
<td>Self Help Groups</td>
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<tr>
<td>SJSRY</td>
<td>Swarna Jayanti Shehri RozgarYojana</td>
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<tr>
<td>SLN</td>
<td>State Level Network</td>
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<tr>
<td>SRTC</td>
<td>State Road Transport Corporation</td>
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<tr>
<td>STI/STD</td>
<td>Sexually Transmitted Infection/Disease</td>
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<tr>
<td>TANSACS</td>
<td>Tamil Nadu State AIDS Control Society</td>
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<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>TDPS</td>
<td>Targeted Public Distribution system</td>
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<td>TGs</td>
<td>Trangenders</td>
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<tr>
<td>TI</td>
<td>Targeted Intervention</td>
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<tr>
<td>TISS</td>
<td>Tata Institute of Social Sciences</td>
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<tr>
<td>TSU</td>
<td>Technical support Unit</td>
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<tr>
<td>ULBs</td>
<td>Urban Local Bodies</td>
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<tr>
<td>UNDP</td>
<td>United Nations Development Programme</td>
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<tr>
<td>UNGASS</td>
<td>United Nations General Assembly Special Session</td>
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<tr>
<td>WLHIV</td>
<td>Woman Living with HIV</td>
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Overview of the HIV Epidemic in India

The epidemic in India shows a declining trend overall. The primary drivers of the HIV epidemic in India are unprotected paid sex/commercial sex work, unprotected anal sex between men and IDU. Given that condom use is not optimal or consistent; men who buy sex are the single most powerful driving force in India’s HIV epidemic. As more than 90 percent of women acquired HIV infection from their husbands or their intimate sexual partners, they are at increased risk for HIV not due to their own sexual behaviour, but because they are partners of men who are within a high risk group (HRG) i.e., clients of female sex workers (FSW), men who have sex with men (MSM) or IDU. The wider implication of this situation is that in almost 6 percent of cases in 2008, the route of transmission of infection was from mother to child.

HIV is diversely spread across states and districts in India. Six high prevalence states, namely, Maharashtra, Karnataka, Andhra Pradesh, Tamil Nadu, Manipur and Nagaland, account for an approximate 66 percent of the HIV burden in the country. Sustained initiatives of Government and stakeholders under NACP III have resulted in reduced adult prevalence estimates in these states. At the same time, reverse trends are emerging in some of the low prevalence categorised states (Rajasthan, Orissa, Uttar Pradesh, Bihar and West Bengal) pointing to a continuously

![Image of HIV transmission modes](source: CMIS, NACO, 2009-10)

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1 This section has been excerpted from NACO (March 2010): Country Progress Report, UNGASS India, pg 14 – 18. Available online at: http://www.aidsportal.org/Article_Details.aspx?ID=15182

2 UNAIDS (2009), 'HIV transmission in intimate partner relationships in Asia'.

3 UNGASS India Country Report: 2010
The changing distribution of the HIV epidemic in India. The low prevalence states in India account for approximately one third of the country’s HIV burden. Among sex workers, there is a decline in south Indian states indicating a possible impact of interventions, while rising trends are evident in the North East suggesting a dual nature of the epidemic now driven both by IDU and sexual transmission (NACO, 2010).

India has 195 priority districts identified according to the prevailing HIV prevalence rates for focused programmatic interventions. Of these, 156 districts are category ‘A’ districts that have over or equal to 1 percent prevalence amongst Anti natal clinics (ANC) attendees. Another 39 districts are category ‘B’ districts with less than 1 percent HIV prevalence amongst ANC attendees but more or equal to 5 percent prevalence amongst Most at risk populations (MARPs) (NACO, 2010).

- **HIV Impact on Households and the need for Social Protection:** Key Facts
  - Increase in household spending: 10% increase in health expenditure by HIV household will reduce their expenditure on education and consumption.
  - Increase in health spending: 5% increase in government health spending on HIV will result in 0.67% decline in government savings and 1.16% in investment.
  - Household income decreases: Illness within the HIV household results in loss of income. 66.25% income lost when PLHIV workers were not working and 9.24% lost due to leave/absence from work.
  - Unemployment increases: Unemployment within the HIV households increased from 3.6% to 9.8% - own illness most important reason. In the 15-60 age group, the workforce participation rate for PLHIV workers was 70.21% in comparison to 51.06% for non-HIV households.
  - Borrowings increase: 46% of HIV households borrowed compared to 27% of non-HIV households.

India is signatory to the Declaration of Commitment on HIV/AIDS 2001, Millennium Declaration in September 2000 and the Political Declaration on HIV/AIDS 2006. In accordance with these commitments, the country has strived to improve and expand its efforts to halt and reverse the HIV epidemic by 2015 and to fulfil its obligations on reporting the status of its response. National AIDS Control Programme – Phase III (NACP – III),...
has placed the highest priority on preventing the spread of HIV from MARPs (FSW, MSM, IDU and bridge populations like short term migrants and truckers), considered as highly vulnerable for HIV and amongst whom the epidemic currently remains concentrated, to the general population.

Mainstreaming as a Response to HIV

Although HIV spreads by ‘risk behaviours’ of people, but risk taking happens in the context of ignorance, power imbalance and socio-economic inequities. Socio-economic conditions (like poverty, lack of livelihood options, rapid urbanisation, labour migration) along with lack of preventive information and services and inadequate dialogue on safer sex have made people more vulnerable to HIV. Loss of life and decreased human capacities due to HIV related illness and death has worsened the economic condition of households especially those with fewer resources, thereby contributing to poverty and inequality. Hence mainstreaming HIV/AIDS in national development programmes is a significant strategy of NACP III to upscale prevention work among the general population as well as improve the capacities of communities to cope with the impact of HIV and AIDS.

A National Council on AIDS, chaired by the Prime Minister and consisting of 31 ministries, nine chief ministers of various states, civil society representatives, positive people’s networks and private sector organisations was constituted in 2006 with the aim of mainstreaming HIV/AIDS issues in all ministries and departments and to provide leadership to a multi-sectoral response to address HIV/AIDS with special reference to youth, women and the workforce. State Councils of AIDS are also formed in 25 states. The focus of NACP III’s strategic plan is advocacy and coordination with 11 key ministries, for extending social protection schemes to the PLHIVs in need of housing, nutrition, livelihood, pension, and other means for survival and improving their quality of life.

To strengthen the mainstreaming efforts, NACO, with support from UNDP, extended technical support to various ministries, established State Mainstream Units (SMU) within SACS and supported Mainstreaming Resource Units (MRU) for technical support to the business sector, civil society organisations and the government departments in the five states of Bihar, Chhattisgarh Rajasthan Uttar Pradesh, Orissa. In all the other states, a Mainstreaming Officer is in place in the respective SACS. A Mainstreaming Cell at NACO steers and monitors the efforts across the country.

This has led to multi-sectoral collaborations with government Ministries and Departments, corporate sector and civil society organisations to make the response to the epidemic as everyone’s agenda. Some highlights of the outcomes of these collaborations include:

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6 www.nacoonline.org
- Addressing HIV issues in rural development schemes.
- Training of elected local representatives, service providers and youth.
- Enhancing care, support and treatment (CST) through linkage with local bodies.
- Preparation of the National Policy on World of Work
- Extending social protection to PLHIV through social pension schemes, food and nutrition schemes, housing, health and employment schemes (NACO, 2010).

An inherent advantage of mainstreaming HIV in State led social protection schemes lies in tapping existing resources than creating new ones. Social protection will help HIV affected households to cope with the impact of HIV related illness and death.

Extending social protection to PLHIV through the State led social welfare schemes or poverty alleviation programmes is rightly receiving attention at the global and national level.

**Rationale and Objectives of the Study**

Extending social protection to PLHIVs through the government sponsored schemes to enable them to cope with the impact of HIV, are receiving attention at the global and national level.

**Objectives of the study**

The major objectives of this research are:
- To list different social protection schemes of government relevant to PLHIVs
- To assess the current utilisation of the social protection schemes by PLHIVs, that will include number of beneficiaries of a particular scheme, funds allotted for the same and financial benefits of the scheme to the target population.

NACO, through multi-sectoral collaborations with government ministries has advocated for amendment/adaptation of policies and schemes for social protection of vulnerable groups. These efforts paved way for positive outcomes like issue of Antyodaya Anna Yojana (AAY) ration cards to PLHIVs in states like Gujarat and Rajasthan, to access food grains at extremely subsidised rates. States like Orissa have extended their Madhu Babu Pension scheme meant for widows and elderly to all PLHIVs residing in Orissa. In Tamil Nadu and Andhra Pradesh, 10 legal aid centres have been established in each state. Advocacy with the Railways Ministry has helped PLHIVs avail 50 percent concession in second class passenger fares for rail travel to nominated ART centres for treatment. Thirty five (35) Integrated and Counselling Centres (ICTC) are presently functional in railway hospitals and ART is also provided to PLHIVs. The ART drugs are procured from the Ministry of Railways budget (NACO, 2010).

Some states in the recent past have intensified their efforts to include PLHIVs in existing social protection schemes while some other states are warming up to this strategy. To develop a better sense of what works and why, it was important to draw on real programming experience.
Understanding Social Protection

Social protection refers to efforts made by the State to reduce poverty and vulnerability not only among individuals, households and communities facing absolute deprivation but also among the currently non-poor in the event of risks/shocks due to unemployment, illness, permanent disability, ageing and so on (The World Bank, Asian Development Bank, ILO).

Asian Development Bank\(^7\) identifies labour market policies and programmes, social insurance programmes, social assistance and welfare service programmes, micro and area based programmes and child protection as the five components of social protection. According to the ILO, social protection is broader than social security because it incorporates non-statutory or private measures as well as public measures, and traditional measures such as social assistance not just social insurance (Garcia and Gruat, 2003).

The World Bank recommends that social protection programmes should be an integral part of poverty alleviation based on the framework for social risk management (The World Bank, 2001).

Social risk management\(^8\)

All population groups, especially the poor, are vulnerable to risks and shocks. The World Bank categorises these risks as idiosyncratic risks and covariant risks.

Idiosyncratic risks include risks related to the following:
- Health – illness (sudden and long term), injury, disability
- Lifecycle – birth, old age, death (especially of breadwinner/head of household)
- Social – crime, domestic violence, robbery
- Gender – control over household resources
- Economic – business failure
- Political - ethnic discrimination

Covariant risks include natural disasters like (earthquakes, floods, famine, pest attack, bad seed quality etc), civil strife or war, financial or currency crisis, political default on social programmes and so on.

The poor are more exposed to risk and have lesser coping mechanisms as compared to those with greater assets and resources. This vulnerability makes the poor unwilling or unable to engage in high-risk/return activities. Poor people resort to informal risk management strategies like asset (land, house, jewellery, cattle, livestock, etc) accumulation in good times, diversification of income sources and creation of family and community risk-pooling

\(^7\) http://www.adb.org/socialprotection/faq.asp

\(^8\) This section on social risk management draws from The World Bank (2001): Social Protection Sector Strategy From Safety Net to Springboard. Washington D.C: The World Bank
arrangements. However, these arrangements can be inefficient to deal with risks or shocks or other socio-economic changes and poor households may cope by reducing human capital (for example, reducing consumption of food, or pulling children out of school to help generate income). This calls for formal risk management strategies through the State to prevent, mitigate and cope with the shocks.

**Social security and social safety nets**

Terms like social security and social safety nets are widely used to imply social protection. Social security often refers to compulsory contributory schemes wherein contributions are paid to a common fund from which the costs of benefits and administration are met. Contributions can be paid by employers and/or the employee (for example, provident fund) and are sometimes subsidised by the State. Old age and health insurance are other examples of this type of scheme.

Social safety nets, on the other hand, refer to non-contributory transfer programmes financed through general tax revenues of a State. These include cash and in-kind transfers, price subsidies, fee waivers, supplementary feeding, public works, microfinance and social insurance targeted at the poor and those vulnerable to poverty and shocks. These programmes help to mitigate or cope with the risk and shocks faced by such individuals/households/communities in times of crises (UNESCAP, 2002).

**Significance of social protection**

Social protection programmes play a role in:

- Providing relief or act as cushion to a vulnerable family by addressing poverty, nutrition or livelihood related risks/shocks
- Transforming livelihoods of poor people, creating assets, stimulating local markets and generating income and employment
- Increasing household income, protecting assets, and reducing vulnerability to shocks, and thus contribute to reducing poverty and hunger, one of the Millennium Development Goals (MDGs) (Garcia and Gruat, 2003).

In the context of international human rights, the right to social protection is enshrined in several human rights instruments adopted by the United Nations, namely the Universal Declaration of Human Rights, and the International Covenant on Economic, Social and Cultural Rights (ICESCR) (ILO, 2010).

**Risks and shocks faced by HIV individuals and households**

The socio-economic impact of HIV/AIDS is more visible at the individual and household level in India due to low national prevalence rates (0.31 percent). An HIV individual and the household face several risks and shocks due to HIV related illness, death, stigma and discrimination which manifest in several ways:

**Increased Spending on Health Care and Treatment**

A study by Mahendra Dev et al\(^9\) (2007) in 3 states of India points out that sudden health

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\(^9\) This study examined some aspects of safety nets programmes in Orissa, Madhya Pradesh and Karnataka based on household and village surveys that were conducted in 2005 – 06 among 1356 households in 9 districts across the 3 states.
A Four State Utilization Study

A socio-economic impact study in India (Pradhan, Sundar and Singh, 2006)\(^{10}\) shows that prevalence rate of both non-hospitalised and hospitalised illnesses was much higher for HIV households as compared to non-HIV households. As per the study, nearly 11 percent of the total consumption expenditure of HIV households was devoted to medical expenses as compared to a mere 3 percent in the case of non-HIV households. In another study carried out in south India (YRG Care, 2004)\(^{11}\), the findings revealed that treatment costs account for an average of 49 percent of household monthly income and reached as high as 81 percent of total household income for clients in the advanced stage of disease and 82 percent for those in the lowest income category. In other words, there is a heavy burden of diseases on HIV households which increases proportionally with the stage of the infection in the PLHA.

Even when a PLHIV sought medical treatment from a government hospital, the household seemed to be incurring out-of-pocket expenditure (in the form of fees and medicine, clinical tests, transport cost, bribes and tips). For example, households incurred an average expenditure of ` 482 per illness episode for treatment of non-hospitalised illnesses and ` 1,434 per hospitalisation case (Pradhan, et al, 2006).

**Loss of incomes**

HIV largely affects individuals in their most productive years. This causes a loss of earnings and incomes of households on various accounts:

- premature death of an AIDS affected earning member of the household,
- reduced earnings due to reduced physical ability to work because of the infection,
- loss of work time of the non-infected members due to the caretaking responsibilities of the infected members, and
- reduced employability due to the stigma associated with the infection (Mahal and Rao, 2005; Barnett and Whiteside, 2002).

The study by Pradhan et al (2006) reported an increase in the percentage of unemployed PLHIV from 3.61 percent (before test) to 9.80 percent (after test). The loss of income for the HIV households varied across occupational and income groups. The impact on wage labourers was significant because absence from work meant no remuneration. For non-working PLHIVs, the income lost as a percentage of current household income was 66 percent and for non-working self-employed non-agriculture people, it was 88 percent.

**Experience of stigma and discrimination**

HIV/AIDS-related stigma and discrimination take different forms and are manifested at different levels - societal, community and individual - and in different contexts like the workplace, health care setting and educational institutions. Stigma and discrimination exacerbate the risks faced

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\(^{10}\) This study titled ‘Socio-economic Impact of HIV and AIDS’, sponsored by UNDP and NACO, and undertaken by NCAER in 2005 for the six high prevalence states of Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur and Nagaland covered 2,068 HIV households and 6,224 non-HIV households spread over both rural and urban areas.

\(^{11}\) A report titled “Maximizing Resources to Meet Client Needs: Evaluation of a Comprehensive HIV/AIDS Care and Support Model in India” prepared by YRG Care, Horizons Program and International HIV/ AIDS Alliance (2004) had data from a cohort of 153 clients of YRG CARE, a leading Chennai based NGO, who had completed the first round of interview during April 2000-October 2001 and follow-up (third) interview from April 2001 to January 2002. A structured pre-tested questionnaire was used to collect the data on out-of-pocket treatment and service related expenditures, loss of income and workdays, and source of finance over a six-month reference period.
by individuals and households as it may lead to denial of household and community care, denial of adequate health care and loss of job or income, as evident from the findings below.

At the household level, women are more likely to be badly treated than men or children. According to UNDP-NACO-NCAER study, more that 80% of widows were forced to leave their married homes after the death of their husbands due to AIDS related illness. Daughters-in-law often find no place in the family for them if the son died (Bharat, 1999). Stigma and discrimination in communities was commonly visible in the form of blaming, isolating, difficulty in procuring a place of stay, teasing and name calling. Household assets are sometimes liquidated to pay for treatment of the husband’s illness, leaving his wife with fewer resources after his death. For example, a wife will sell her gold or other jewellery for quick cash to cover health expenses. In other cases, the marital family may deny her claim to the matrimonial property after her husband’s death because they equate their contributions for treatment to the husband’s share of the family inheritance.

A New Delhi based study (Mahendra et al, 2006) revealed that Stigma and discrimination was manifested in health care settings in the form of unwarranted referrals to other facilities, condescending, judgmental, and moralistic attitudes among staff, segregation and labelling of patients, excessive use of barrier precautions by staff, HIV testing without consent or disclosure of test results to family and non-treating staff without consent.

Discrimination at the workplace manifested through attitude of co-workers like neglect, isolation, avoiding close proximity, abuse, teasing and name calling. According to the study by Pradhan et al (2006), fear of losing their job, social discrimination and lowering of prestige were the main reasons for PLHIVs not disclosing their HIV status at their workplace. The small percentage of the sample who shared their HIV status at the workplace, faced several discriminatory practices like being forced to resign or take voluntary retirement, denial of promotion and benefits and refusal of loan facilities.

Children whose HIV status was known to the school were denied access to education and were often ostracised on grounds that the positive child may infect others; he/she would have negative impact on other children etc. which were based on ignorance and myths about the disease.

**Coping mechanisms of HIV individuals and households**

**Reduction in Consumption and Savings**

The HIV households liquidate their fixed assets in order to cope with the burden of the medical expenses. The asset most likely to be liquidated is a house or a land in the rural areas. This movement away from fixed assets to relatively liquid assets has important long-term implications for households as it implies a loss of wealth and a lowered capacity to deal with external shocks in the future. Households also tend to borrow money from local moneylenders at high interest rates. For example, nearly 46 percent of HIV households had borrowed as compared to around 27 percent of non-HIV households, in the last one year, as depicted in Pradhan et al (2006). Similarly, almost 43 percent of HIV households had either borrowed or liquidated assets after one of the family members tested positive.

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12 Women’s property rights as an aids response: ICRW, 2007
Food consumption is also lowered in HIV households to cope with increased spending on health and reduced income. This is evident from the study finding that HIV households engaged in wage labour devoted a lower percentage of total expenditure to food as compared to the wage labour group among non-HIV households.

**Withdrawing children from school**

Studies indicate that children of HIV households drop out of school either to reduce expenses or to take care of siblings or contribute to the household income by engaging in work. Those who continue with education often find it difficult to balance school and household work and eventually quit school (Nadkarni and Soletti, 2006; Pradhan, et al, 2006). In other cases, orphaned children have to depend on grandparents, extended family members or NGOs for care and support. A study on child-headed households in Tamil Nadu and Andhra Pradesh revealed that support from family and relatives is often superficial and without financial help. Grandparents are able to extend psychological support, but have little to offer when it comes to financial help (Nadkarni, et al, 2006). Lack of education reduces the future capacities of these children to engage in skilful employment thereby contributing to the poverty situation of such households.

**Increasing the number of members joining the work force to supplement reduced incomes**

Other members of HIV households are required to supplement the earnings of male members in order to compensate for the mounting medical expenses and loss of income of HIV infected male members. It is not only the PLHIV who suffer loss of income and employment, but also other members of the HIV household who have to perform twin functions of the caregiver’s role and contribute to the income of the house, albeit, this is more pertinent in the advanced stage of the infection.

The coping mechanisms of all HIV households are not uniform. Better resourced HIV households have a greater resilience to cope with the long term impacts of AIDS as compared to the poor households because the latter are already struggling against difficult circumstances

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**Coping mechanisms of households to deal with risks/ shocks associated with HIV and AIDS**

- Households cope by reducing expenses on essential items, including food.
- Women (if not already working) feel forced to join the workforce. Women without skills often settle for non-skilled jobs with smaller incomes.
- School dropout is seen as a way of reducing expenses or to have helping hands for the domestic work at home.
- Households with assets resort to selling them.
- Households without assets tend to borrow money from informal credit sources like relatives or local moneylenders at higher interest rates.
- Households with more than one ill person and without any assets could be pushed towards destitution that could result in dissolution of the household or complete dependence on charity.

Source: Pradhan, Sundar and Singh (2006); Mahal and Rao (2005); Basu, Gupta and Krishna (1997)
like poverty, illiteracy, mobility and displacement, inequities of class and sex and lack of access to health or life insurance cover (Basu, Gupta and Krishna, 1997). PLHIVs and their families need support through social protection in order to cope with the HIV related illness and death. Social protection in the form of health care, insurance, food and nutrition, school fee waivers, organised livelihood options would help to prevent the HIV household from impoverishment and disintegration.

Social protection in India
The Directive Principles of State Policy in the Constitution of India enjoin upon the State to undertake within its means a number of welfare measures. These are intended to secure for the citizens adequate means of livelihood, raise the standard of living, improve public health, provide free and compulsory education for children etc. In particular, Article 41 of the Directive Principles directs the State to provide public assistance to its citizens in case of unemployment, old age, sickness and disablement and in other cases of undeserved want within the limit of its economic capacity and development.

Welfare schemes and poverty alleviation programmes that have been integral to the different five year plans of the Indian government. India spends annually about 2 percent of GDP on such programmes funded by the central government (Mahendra Dev et al, 2007).

Schemes target the vulnerable
These schemes mainly target different vulnerable groups and communities who suffer social and economic disadvantages. These mainly include women, children, elderly, persons with chronic diseases like cancer, TB, etc. persons with physical or mental disability, those marginalised on grounds of caste, class and other deprivations. These individuals or households need to have an income less than specified in order to be eligible for social protection schemes (GoI, 2006).

In this research study, the different social protection schemes have been broadly segregated into common themes, for example, social pension schemes, food and nutrition schemes, wage/self employment schemes, housing schemes, etc. States have also introduced independent programmes in addition to the centrally sponsored schemes. The following schemes are described below:

- Social pension schemes
- Food and nutrition schemes
- Wage/self employment schemes
- Housing schemes
- Unorganised Workers Social Security Act

(Details regarding the eligibility and entitlements of each of the schemes are given in Annexure-1).

Social Pension Schemes
India’s national and state social pension schemes aim to address chronic poverty through regular cash transfers to destitute elderly, widows and disabled people who have no regular means of subsistence from their own sources of income or through financial support from family members or other sources. In 1995, the Government adopted the National Social
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Assistance Programme (NSAP), which is made up of the following components: the National Old Age Pension Scheme (NOAPS), the National Family Benefit Scheme (NFBS), the National Maternity Benefit Scheme (NMBS) and the Annapurna Yojana.

Food Security Schemes
There are schemes to ensure food security of the poor and vulnerable in our country. Generally, the benefits are in the form of food subsidies and supplementary nutrition. Examples of the food and nutrition schemes include:

- **Public distribution system (PDS)**\(^{13}\): Since 1951, the PDS plays an important role in the provision of food security to the people of India. It is a means of distributing food grains and other basic commodities at subsidised prices through fair price shops (FPS). Every family is supposed to have a ration card. In 1997, the PDS became targeted – TPDS: wherein different ration cards were issued to households, BPL and APL, and each category has different entitlements.

- **Antyodaya Anna yojana (AAY)**\(^{14}\): launched in December, 2000 is aimed at making the TPDS more focused towards reducing hunger in the destitute households/chronic poor.

- **Integrated Child Development Scheme (ICDS)**\(^{15}\): ICDS represents one of the world’s largest programmes for early childhood development through a chain of anganwadis who provide education and specific health services to pregnant and lactating mothers and children (0 to 6 years).

- **Mid-day meal scheme (MDMS)**\(^{16}\): began in April 2002, in which every government run or government-aided primary school, in every part of the country is to provide a nutritious, clean hot cooked meal to all primary and upper primary school children.

- **Annapurna Yojana**: following the institution of the NSAP in 1995, the GoI introduced a food security scheme, called Annapurna yojana, in April 2004. This scheme provides food security to older destitute persons, who though eligible, have remained uncovered under NOAPS.

- **National Food Security Bill, 2010**\(^{17}\): This bill, currently being debated by the Parliament aims at universalisation of food grain entitlements across the country in which there shall be a guarantee of 25 kgs of foodgrains (such as rice or wheat) to every identified BPL household at subsidised prices. Issues relating to fiscal liability of the food subsidy proposed in the bill and poverty estimates remain to be addressed before this bill is passed.

Wage Employment/ Self-Employment Schemes
Wage employment scheme like MGNREGA and self employment schemes like SGSY and SJRY are significant in reducing poverty as they provide livelihood options to targeted beneficiaries. They have also been useful to reduce short term migration from rural to urban areas.

- **Mahatma Gandhi National Rural Employment Guarantee Act (MGNREGA)**\(^{18}\): was launched in February 2006 with the aim of providing 100 days of employment in a financial year to any rural household whose adult members are willing to do unskilled manual work. Although all households are eligible, the expectation is that only the poorer sections, that is,

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\(^{13}\) www.uidai.gov.in (as accessed on March 2, 2011)

\(^{14}\) www.facmin.nic.in (as accessed on March 2, 2011)

\(^{15}\) www.wcd.nic.in/icds (as accessed on March 2, 2011)

\(^{16}\) www.righttofoodindia.org (as accessed on March 2, 2011)

\(^{17}\) www.righttofoodindia.org/data/egom_draft_bill2010.pdf (as accessed on March 2, 2011)

\(^{18}\) www.nrega.nic.in (as accessed on March 3, 2011)
landless labour and marginal farmers would actually seek work. The secondary aim was to ensure that employment generated is from works that raise land productivity.

- **Swarnajayanti Gram Swarozgar Yojana (SGSY)** - was launched in April 1999 by the MoRD by restructuring the IRDP, DWCRA, TRYSEM and other schemes for self-employment of the poor. The target group of this scheme is the BPL families and within this special safeguards have been provided to vulnerable sections, by way of reserving 50% benefits for SCs/STs, 40% for women and 3% for disabled persons. The basic objective of SGSY is to bring the BPL families above the poverty line by providing them income-generating assets through a mix of bank credit and governmental subsidy.

- **Swarna Jayanti Shahari Rozgar Yojana (SJSRY)20** - in operation since 1997, but revised guidelines came into effect from April 2009. This scheme aims to address urban poverty through skill training and gainful employment to the urban unemployed or underemployed poor. The scheme is implemented through the medium of Urban Local Bodies (ULBs) and community structures.

### Housing Schemes

Housing scheme like the Indira Awas Yojana (IAY)21 aims to provide assistance for construction/upgradation of dwelling units to the BPL rural households, with preference to SCs, STs and freed bonded labour categories.

### Unorganised Workers’ Social Security Act, 2008

This Act (Bill prepared by the National Commission for Enterprises in the Unorganised Sector) which came into effect from May 2009, aims to provide minimum social security to the huge workers population in the unorganised sector. It mentions ten schemes in the schedule which include Aam Admi Bima Yojana, Rashtriya Swasthya Bima Yojana, Janshree Bima Yojana, Janani Suraksha Yojana, Old Age Pension, Family Benefit and schemes related to weavers, artisans and master crafts persons. Many of the schemes mentioned in this Act (Eg: JSY, NOAPS, etc) are already available to all BPL populations in the country. The Act has been critiqued by scholars for the exclusion of sections of unorganised workers like agricultural labourers and the unorganised labourers in the organised sector (Ghosh, 2009).

- **Aam Aadmi Bima Yojana (AABY)22** - is a scheme for the rural landless households, wherein the head of rural landless families or one earning member in each such family will be insured. This scheme is administered through LIC, India.

- **Rashtriya Swasthya Bima Yojana** - was launched by Ministry of Labour and Employment, to provide health insurance coverage to BPL households. Beneficiaries are entitled to hospitalisation coverage up to ₹30,000.

- **Janani Suraksha Yojana (JSY)24** – is aimed at reducing maternal and infant mortality rates and increasing institutional deliveries in BPL families. It covers all pregnant women belonging to households below the poverty line, above 19 years of age and up to two live births.

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19 [www.sgsy.gov.in](http://www.sgsy.gov.in) (as accessed on March 4, 2011)
20 [www.sjsry.gov.in](http://www.sjsry.gov.in) (as accessed on March 4, 2011)
21 [www.india.gov.in](http://www.india.gov.in) (as accessed on March 4, 2011)
22 [http://www.licindia.in/aam_admi_benefits.htm](http://www.licindia.in/aam_admi_benefits.htm) (as accessed on March 4, 2011)
Though several schemes discussed above are centrally sponsored, they are implemented by the state governments. Due to this, there is variation in the implementation of schemes across states.

**Unique Identification Number (UID) – Aadhaar project**

The UID – Aadhaar project in India aims to provide a unique identity number to the applicant so that the problem of leakages in several poverty alleviation programmes is laid to rest. No person can have a duplicate number since it is linked to their individual biometrics. Savings from eliminating duplicates and fakes through Aadhaar-based identification will further enable the government to expand benefits to other eligible persons.

**BPL Household Identification**

As evident in the eligibility criteria of the social protections schemes discussed above, BPL identification is necessary to secure benefits of the anti poverty programs like social pension schemes, food grains at subsidised rates from PDS, scholarships, insurance schemes, housing schemes and other social welfare schemes of the State government. The identification of BPL households in both rural and urban areas is therefore very crucial for the effective implementation of poverty alleviation programmes in the country.

The estimation of the poverty at the National and State level is done separately for rural and urban areas, by the Planning Commission. The Ministry of Rural Development has been conducting BPL Census surveys since 1992 based on uniform methodology/parameters to identify the BPL households in the rural areas.

**Performance of the social protection schemes in India**

There are several evaluation studies on the effectiveness of social protection schemes in India. These studies suggest that most of the schemes suffer from weaknesses such as poor targeting and coverage, leakages in benefits, low benefit size, inadequate institutional arrangements for delivery, limited funds or delays in release of funds and inadequate monitoring of outputs. Reviews of few social protection schemes are discussed below.

**Distribution of central government spending across social protection schemes, 2008–09**

As per the central government spending on social protection schemes for the year 2008–09, 49 percent of the budget was spent on subsidised food (which includes food and fuel subsidies and mid-day meals), 33 percent for public works (which includes MGNREGA and SGRY), 7 percent for rural housing (IAY), 4 percent for social pensions, and 5 percent for others which (includes welfare schemes for SC/ST, RSBY, central welfare funds and urban social protection) (Dutta, Howes and Murgai, 2010).

**Targeted Public Distribution System**

Several evaluation studies on the TPDS highlight that poor targeting (high exclusion and inclusion errors), non-viability of FPSs, failure in fulfilling the price stabilisation objective, and leakages continue to ail this oldest, largest and expensive food based programme (Jha, Gaiha and Pandey, 2010; Gol, 2008; Mahendra Dev, Subbarao, Galab and Ravi, 2007). The Planning Commission (Gol, 2008) points out that TPDS covered only 57% of
BPL families. Errors of inclusion were high in Andhra Pradesh, Karnataka, and Tamil Nadu thereby implying that APL households received a large proportion of subsidised grains. During 2003–04, it was estimated that out of 14.1 million tonnes of BPL quota from the Central Pool, only 6.1 million tonnes reached the BPL families and 8 million tonnes did not reach the target families. This leakage and diversion raised the cost of delivery. For every 1 kg that was delivered to the poor, GoI had to issue 2.32 kg from the Central Pool. Mahendra Dev et al (2007) opined that weak targeting enforced by the BPL lists had resulted in diversion of benefits of PDS to non-poor households.

The Planning Commission (GoI, 2008) has proposed some of the following to address systemic problems through the new food security bill:

- Smart Cards through the UID – Aadhar project to eliminate bogus or shadow ration card holders.
- Roaming Ration Cards providing an opportunity to short-term migrants to move their ration cards to their new area or work.
- Direct Cash Transfer Program where the subsidy could be transferred into the bank account of the beneficiary.
- Choice of Fair Price Shops - to improve quality of service and this solution allows the incorporation of either limited or full choice of FPS.
- Food Stamps - to allow competition from existing food shops and increasing the reach of the TPDS network.
- Web enabled systems to allow easy access to such information and thereby empower the beneficiaries.

Social Pension Schemes
An evaluation study (Dutta, Howes and Murgai, 2010) on social pension utilisation in the elderly and widows, in two states, Karnataka and Rajasthan, revealed that the performance of social pension schemes appeared to out-perform the PDS. Though the former had lower coverage, both schemes targeted the poor and vulnerable, but the social pension schemes had much lower leakage. Bribes might have to be paid to join the scheme, but once a pensioner was on the list there was little scope for further diversion of funds, at least on a large scale. In comparison, extraction of benefits was a challenge every time wherein users had to persuade the shopkeeper to open his shop and sell the foodgrains to them rather than to divert. The researchers suggest that the low leakage is either because of the low levels of discretion involved in their delivery, or the small size of the transfers involved. They further caution that scaling-up of the social pension schemes, while warranted, will need to be closely monitored.

National Social Assistance Programme
A quick evaluation study of NSAP done by the Centre for Management Development, 2000 (cited in GoI, 2006) highlights that the NOAPS was found to be extremely beneficial to the old destitute. In general, it had succeeded in giving them a sense of security in life and has definitely improved their quality of life.

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25 This study was based on special purpose household surveys carried out in Karnataka (2005) and Rajasthan (2006) and nationwide 41,000-household India Human Development Survey (IHDS) reported in Ajwad M. I. (2006) 'Coverage, Incidence and Adequacy of Safety Net Programs in India', Background Paper prepared for Social Protection for a Changing India, World Bank.
However, cumbersome registration procedures requiring numerous proofs of varying nature across states, arbitrary numerical ceiling for the number of programme beneficiaries, low awareness level among the potential/eligible beneficiaries were cited as some of the constraining factors in accessing NSAP (ORG, 1998 cited in GoI, 2006). This report by GoI (2006) recommended that the NSAP needs to re-look into the numerical ceiling norms, make provision for updating BPL list, clearly define responsibility among the various functionaries involved in the implementation (the district collectorate, BDO, AWW, ANM, etc), ensure timely release of benefit and lay greater emphasis on publicity and awareness generation as steps to address the constraints.

**Wage/ Self employment Schemes**

Ministry (2011)\(^{26}\) points out that awareness about MGNREGA led to better implementation of the programme. A study by Jha, Gaiha and Pandey (2010) in the 3 states of Rajasthan, Andhra Pradesh and Maharashtra explored the net transfer benefits under MGNREGA in the light of opportunity cost of time (since participants had to travel distances to reach the job site). In general net transfers under the MGNREGA were found to be quite modest. Activists\(^{27}\) have expressed concerns about issues like non-payment of minimum wages, delays in wage payments, insufficient scale of MGNREGA works, discrimination against Dalits and women that need attention of the government.

The SHGs have performed very well in the area of thrift, saving and small personal loans primarily for non-productive purposes. But they have made little headway in promoting income generating activities (Rao, 2007). Mahendra Dev et al (2007), in their study on outreach and effectiveness of safety net programmes in Orissa, Karnataka and Madhya Pradesh found that a high proportion of beneficiaries of credit-based micro finance programme (SGSY) belonged to the richest quartile indicating that non-poor households are benefitting from this programme.

**Housing scheme**

Similarly for the housing scheme, IAY, Dev et al (2007) found that gaining “entry” into this scheme required households to possess enough networking ability. This scheme with a large cash transfer was attracting households in the upper quartiles. Substantive abuses and corruption in the actual implementation of this scheme also emerged in the study.

Overall, the study by Dev et al (2007) suggests that awareness about a scheme is a precondition for participation but does not guarantee participation. Other factors like caste, occupation of the household, literacy, household size, sex of the head of the household, social capital of households, women’s autonomy and participation, village level characteristics like social and economic infrastructure and the functioning of PRIs influence participation of the target population in a given scheme. Literacy in a household and women’s empowerment play a positive role in the uptake of child related education schemes.

According to Rao (2007), the poverty alleviation programmes in India have operated in a top-down manner favouring the upper layers of poor and those in relatively developed states. He suggests that for such programmes to be effective, the social protection schemes need to strengthen the status of the hardcore poor and lead them to the point where they acquire

\(^{26}\) http://www.dnaindia.com/money/analysis_analysis-mgnrega-is-a-perfect-tribute-to-mahatma-gandhi_1505396

\(^{27}\) http://www.hindu.com/2010/12/01/stories/2010120164301300.htm
capabilities and motivation to take development initiatives on their own. Decentralisation and strengthening of PRIs has also been recommended by several researchers for the effective implementation of the social protection schemes.

Some researchers are proposing a radical change from subsidy to cash transfers based on the success of certain Latin American models, as an alternative to counter leakages. For example Kapur, Mukhopadhyay and Subramaniam (2008) have advocated for a case of direct cash transfers (DCT) to the poor households in lieu of complicated schemes. Mehrotra (2010) suggests the conversion of subsidies into five conditional cash transfers (CCT) aimed at BPL families, BPL mothers, BPL children and BPL youth. However, systems like identification of poor and vulnerable along with a biometric identity card and post office or bank account will need to be put in place prior to initiating DCTs or CCTs.

Summary
This chapter has explained the vulnerabilities of HIV households to risks/shocks associated with HIV related illness and death. Increased health expenditure, reduced income/earnings along with stigma and discrimination are the major risks faced by HIV households who cope by reducing consumption of essential items like food, withdraw children out of school and women may perform the dual role of caregivers as well as join the workforce to bring income. The strategy of linking HIV households to the different central/state government social protection schemes is gaining significance so that the vulnerable households feel cushioned against the risks/shocks that HIV related illness, death stigma and discrimination bring with it.

India has, in its different five year plans, devised several poverty alleviation programmes to provide social protection to the poor and vulnerable groups. The programmes have aimed to address food security, livelihood needs, health care and housing through different schemes like the PDS, ICDS, MDMS, MGNREGA, SGSY, JSY, IAY, widow/old age pensions and so on. Although several studies have evaluated the performance of different social protection schemes mentioned above, there is no literature documenting the experiences of HIV households in accessing the social protection schemes since this is a relatively recent strategy.

Evaluation studies by researchers as well as GoI reports have acknowledged poor targeting and coverage and leakages of benefits as major roadblocks in way of effective implementation of the schemes. BPL surveys are crucial since majority of the social protection schemes are targeted to households below the poverty line. However inclusion and exclusion errors in the BPL surveys have left out many poor households whereas non-poor households have found inclusion. The eleventh five year plan (2007 – 2012) has envisaged the UID – Aadhar project along with newer parameters to identify the BPL households to improve the reach of the different social protections schemes. These new projects are either at their infancy or are still being debated and hence it would be too early to review their effectiveness.

Since the uptake of social protection schemes by PLHIVs is at a very nascent stage, this research study aims to understand the facilitating factors in accessing the social protection schemes to draw strength from them and develop successful strategies. Understanding the constraining factors will help to plan interventions to plug the gaps. In other words, this study will be useful to develop suitable mainstreaming strategies to cope with the risk of HIV on individuals and households.
References


Chapter 2

Methodology

This chapter covers the research questions, research design, study location, sampling method, data collection process, method of data analysis and finally the limitations of this study.

Research Questions
- What are the different social protection schemes that PLHIVs are availing of?
- To what extent are the schemes accessed? Are the benefits substantial?
- What are the facilitating and the constraining factors for accessing the social protection schemes?
- What could be the cumulative benefit package that could be offered to a PLHIV?

Research design
The study is exploratory and descriptive in nature through use of qualitative in depth techniques, in which different social protection schemes used or not used by PLHIVs and their experiences in accessing the schemes are analysed.

Study Location
The study was conducted in the four states in India namely, Gujarat, Orissa, Rajasthan and Tamil Nadu. These four states were purposively selected for the study to have regional representation as well to include states with different HIV prevalence rates. One high HIV prevalence state namely Tamil Nadu and one moderate HIV prevalence state Gujarat was selected. Orissa and Rajasthan were low prevalence states. The other criterion was to ensure a mix of states with different levels of mainstreaming activities initiated by UNDP and SACS in these states.

<table>
<thead>
<tr>
<th>State (Region)</th>
<th>HIV prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tamil Nadu (South)</td>
<td>High</td>
</tr>
<tr>
<td>Gujarat (West)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Orissa (East)</td>
<td>Low</td>
</tr>
<tr>
<td>Rajasthan (North)</td>
<td>Low</td>
</tr>
</tbody>
</table>
Research Team
The research team comprised of the Principal Investigator (PI) along with two research officers (with a background in social work education and several years of work experience in health and HIV/AIDS sector). The data collection was done simultaneously by the research officers in two states at a time. The senior research officer carried out the data collection in Tamil Nadu and Orissa while the second research officer did data collection in Rajasthan and Gujarat. Research assistants were hired in Tamil Nadu and Orissa for the period of data collection to facilitate the FGDs and few KIIs in the regional language. In Rajasthan and Gujarat, research assistants were not required as the FGDs and KIIs were conducted in Hindi, a language the research officer was fluent in.

Profile of participants
To include the 360 degree perspectives on social protection schemes, stakeholders at different levels were included in the study through a purposive sampling method. Focus group discussions were held with the end users, that is, PLHIV users as well as non users of the social protection schemes. The PLHIV users/non-users were members of the State level Network (SLN) or District Level Network (DLN) in the state. The key informants included SLN/DLN representatives in leadership positions who were promoting the schemes among PLHIVs, representatives of NGOs advocating the schemes and officials from the mainstreaming unit in SACS, who are advocates as well as represented the implementing agency.

To attain gender balance, equal numbers of men and women participants from the end users group as well as among the key informants from the SLN/DLN were included.

<table>
<thead>
<tr>
<th>State (Region)</th>
<th>Key Informant’s Interview</th>
<th>FGD participants</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>NGOs</td>
<td>SACS</td>
<td>PPNSs</td>
</tr>
<tr>
<td></td>
<td>S</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Gujarat (West)</td>
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<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Orissa (East)</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Rajasthan (North)</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Tamil Nadu (South)</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>6</td>
<td>4</td>
</tr>
</tbody>
</table>

Selection of Participants

Key Informants
The selection of the key informants among the positive people’s networks and SACS was done on the basis of suggestions from the state mainstreaming units as well as active NGOs involved in the work of reaching the social protection schemes to PLHIVs. Similarly key informants among NGOs were selected on the basis of suggestions from the state mainstreaming unit as well as positive people’s networks. Accessibility of the NGOs and availability of the participants was also considered, so as to complete the data collection in the limited time available in each state.
**FGD participants**

Two FGDs with users (one with women and the other with men) and one FGD with non users (mixed group of men and women) were conducted in each state. However, in Tamil Nadu, the non-users’ FGD was conducted separately with men and women since the positive men’s and women’s networks were not on cordial terms with one another. A separate FGD for women and men (in non-user’s category) provided opportunity for the women’s network to invite more participants and therefore women outnumbered men in the number of FGD participants (see table on sample size). This does not necessarily imply that more women were non-users of social protection schemes or vice versa.

The research team discussed the criteria for selection with the office bearers of the SLN/DLN and the participants for the FGDs were selected by them based on the predetermined criteria as follows.

The person had to be a PLHIV or from a household affected by HIV/AIDS (spouse, parents, grandparents, siblings etc.)

- He/she had accessed, availing or availed of at least one of the schemes (in case of non-users -not accessed any of the schemes) from the list mentioned below:
  - Nutrition/food security (ICDS, AAY, Annapurna yojana, PDS, MDMS)
  - Travel concession for ART treatment
  - Pension schemes (for Widow, Old age or PLHIV)
  - Livelihood schemes (NREGA, SGSY, SJSRY)
  - Janani suraksha yojana
  - Housing schemes (Indira Awaas Yojana)
  - Legal aid
  - Any other government scheme available in the state

- Willing to share his/her experiences in accessing the social protection schemes.
- Willing to give 4 hours time for data collection including the travel time.
- Not staying far from the meeting place (not more than 20 kms)
- Understand the regional language and/or English/Hindi
- It is to be noted that this study focused on central/state government financed social protection schemes.

**Data Collection Tools**

Both quantitative and qualitative data was collected for the study. Quantitative study was conducted through secondary sources of data while qualitative data was conducted through primary sources as follows.

**Qualitative data**

The following qualitative data was collected through primary sources of data collection using a semi structured interview schedule with key informants and focus group discussion guide with PLHIVs *(Refer to Annexures 4, 5 and6 for the KII and FGD guides).*

- Experiences of the users and non–users in accessing the social protection schemes
- Relevance and advantages/disadvantages of the scheme
- Benefits of the scheme and satisfaction/dissatisfaction with the same
- Gender aspects in accessing the schemes
- Facilitating factors and barriers in accessing the schemes
- Strategy of mainstreaming v/s targeting

Quantitative data
The following quantitative data was collected through the government websites, published and unpublished reports of SACS, state mainstreaming units and the positive people’s networks.

- Funds allotted and spent/utilised for the schemes at the state level
- Number of users of different programmes/schemes at the state level
- Number/proportion of PLHAs availing the schemes

Process of development of the tool
The draft interview schedule and the FGD guide was prepared on the basis of research questions and areas of enquiry. The interview schedule was pretested with one of the PPN office bearers from Maharashtra. The FGD guide was translated in Marathi and pretested with users and non users of the social protection schemes in Maharashtra, that is, with a group of PLHIVs from a district level network in Thane. Both the tools were modified to remove the repetitive information and to facilitate better flow and logical sequence of questioning.

The researchers, being fluent in Hindi, translated all the three tools and the consent form in Hindi. Both the English and Hindi tools were shared with professional translators for translations in other regional languages, namely, Gujarati, Oriya and Tamil. Every 5th question of the regional language tool was back translated in English to check the quality of translations.

Data collection Process
The research team members contacted all the identified key informants for appointments and planned the data collection schedule in consultation with the SLN/DLN leaders and mainstreaming unit of the respective state. A coordinator or a point person from each SLN/DLN was identified to coordinate the FGDs. Key informant’s interviews were conducted in English and regional language, as per the choice of the participant. All the FGDs were conducted in regional languages.

Each interview and FGD lasted for minimum of 2 hours and maximum of 3 hours. In Tamil Nadu and Orissa, the local research assistant translated, and facilitated the FGDs and interviews in the regional language and also recorded the field notes. The assistants were given orientation about the study and research tool was sent to them in advance. Incidentally, in one of the states the research assistant translated the tools in regional language which facilitated familiarity with the study.

Total of 25 interviews, 8 FGDs with users and 5 FGDs with non users were conducted in all the states.

All the KIIIs and FGDs were audio recorded after receiving consent from the participants. Field notes were also taken. Recorded interviews and FGDs were transcribed and translated in English.
Ethical considerations

The choice to participate in the study was sought from all participants through a consent form that outlined the purpose and method of the study, implications of participating in the study along with the option of opting out at any time during the study (Refer Annexure 7 for the consent form in English). The interviews and FGDs were scheduled according to the convenience of the participants. The research team had fixed appointments with most of the key informants based on their availability and convenience, prior to departing for data collection. Confidentiality was maintained by keeping the data anonymous. A code number was assigned to each of the participants, and used for the analysis.

Time Frame

This research project was initiated in the month of July 2010 and was completed in 8 months. The time line is presented in the table below:

<table>
<thead>
<tr>
<th>No.</th>
<th>Activity</th>
<th>Jul</th>
<th>Aug</th>
<th>Sept</th>
<th>Oct</th>
<th>Nov</th>
<th>Dec</th>
<th>Jan</th>
<th>Feb</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Recruitment of research consultant and research officer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>2</td>
<td>Finalizing the research proposal</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Developing the research tools and field testing the tools</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Finalizing research tools</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>5</td>
<td>Translation and typing of research tools in Hindi, Gujarati, Oriya and Tamil</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>6</td>
<td>Back translation of research tools to check accuracy in translation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>7</td>
<td>Initial Contacts with the SACS officials, prospective NGOs and PPNSs to serve as a local contact for FGDs in their State.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>8</td>
<td>Data collection for 5 days in each of the state (total 22 days inclusive of travel)</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Transcriptions of the recorded data and translations (from regional languages to English)</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Coding of data and analysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>11</td>
<td>Draft Report</td>
<td></td>
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<td></td>
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<td>12</td>
<td>Draft report submission to UNDP</td>
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<td></td>
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<td></td>
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</tr>
<tr>
<td>13</td>
<td>Final report submission to UNDP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Method of Data Analysis
A code sheet was developed by the two team members of the research team by coding one interview each and then sharing the codes. The transcribed data from the interviews and FGDs were coded by using Atlas Ti (5) software for qualitative analysis. Code sheet was updated every time a new code was created for newer information in the transcribed interviews. Coded data were segregated as per thematic schemes across all states to do a scheme wise analysis. This analysis helped to understand the facilitating and constraining factors across all schemes as well as highlight the successful strategies in increasing the utilisation of social protection schemes by PLHIVs, which are discussed in the subsequent chapter 3 on Findings. Chapter 4 presents the he summary findings and conclusions and lastly the suggestions and recommendations. The annexures have details about the different social protection schemes in India and the data collection tools and the consent form.

Field Experiences during Data collection
All the participants showed great interest in participating in the study. Many expressed that the questions in the interview made them reflect on their work and they would like to include some of the aspects in the questionnaire as a monitoring guide for their work in future. Many participants also expressed that the study findings will give them an opportunity to learn good practices as well as strategies used by the other states for mainstreaming PLHIV in the social protection schemes.

Scope and Limitations of the study
This study being a qualitative one provides the overall trends in the roll-out of social protection schemes. It clearly brings out the facilitating and constraining factors for PLHIVs in accessing the various social protection schemes. The study also documents some successful strategies that emerged from the experiences of implementation and accessing of social protection schemes by PLHIVs in the four select states. Case studies have been discussed to explain the successful strategies which maybe useful to other states for cross learning and could be considered for replicating within the local context.

The study participants mainly comprised of PLHIVs registered with the state or district level network. It was observed that participants who were SLN/DLN staff had greater awareness about social protection schemes as compared to the others. This study has not been able to capture experiences of PLHIVs not registered with the networks. It will be useful to understand experiences of access of social protection schemes by PLHIVs not registered with the PPNs through further studies.

Language barrier in Orissa and Tamil Nadu led to a dependency on local research assistants for conducting focus groups discussions in the regional languages. This has possibly affected the in-depth probing of certain topics in the FGDs.

The study participants did not have sufficient representation from the most at risk populations like FSWs, MSMs and TG groups to analyse the specific barriers that these groups may face in accessing the social protection schemes. There is a need to explore these issues and develop ways to enable utilisation of social protection schemes by FSWs, MSMs and TGS among PLHIVs.
One of the objectives of the study was to assess the current utilisation of the social protection schemes by PLHIVs by analysing the funds allocation from the central/state government for each scheme, the funds utilised vis-a-vis the total number of beneficiaries of the scheme. Although, it has been possible to collect limited data from central/state government websites and scheme specific websites on the funds allocated to each scheme and the total number of beneficiaries (refer to Annexure – 2 for data), there was lack of data on the number of PLHIV specific beneficiaries. The state and district level networks and NGOs in all the states had some data on the number of PLHIV beneficiaries of schemes, but this pertained to those PLHIVs registered with their network or whom they had assisted in applying for the same.

Further, there was data on the estimated PLHIV population in a given state, but, this data did not provide information on the number of HIV widows. Hence, it was rather difficult to assess the percentage of HIV widows accessing schemes like widow pension and NFBS that are specifically targeted to them.
Chapter 3

The Findings

This chapter presents the major findings of the study. These are organised around the following major themes presented in different sections:

Section 3.a
- Social protection schemes (both central and state sponsored schemes) currently accessed by PLHIVs in the four states of Gujarat, Orissa, Rajasthan and Tamil Nadu.
- Facilitating factors in the uptake of social protection schemes by PLHIVs.

Section 3.b
- Constraining factors in the uptake of social protection schemes by PLHIVs.

Section 3.c
- Gender related aspects in accessing social protection schemes.
- Mainstream social protection schemes versus target schemes for PLHIVs.

Section 3.d
- Successful strategies in the uptake of social protection schemes by PLHIVs.

Before discussing the aforementioned major themes, a socio-demographic profile of the focus group discussion participants, that is, the end users or non-users, is presented below (Refer to table 1 and figures 1, 2 and 3). This profile represents a cross section of the PLHIVs in the four states whose experiences of accessing the different schemes are captured in this study.

Table 1: Socio-demographic profile of the FGD participants (both end users and non-users of different social protection schemes)

<table>
<thead>
<tr>
<th>AGE GROUP (in years)</th>
<th>Guj</th>
<th>Ori</th>
<th>Raj</th>
<th>TN</th>
<th>Total</th>
<th>Guj</th>
<th>Ori</th>
<th>Raj</th>
<th>TN</th>
<th>Total</th>
<th>Grand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MEN</td>
<td>WOMEN</td>
<td>MEN</td>
<td>WOMEN</td>
<td>MEN</td>
<td>WOMEN</td>
<td>MEN</td>
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<td>MEN</td>
<td>WOMEN</td>
<td>MEN</td>
</tr>
<tr>
<td>less than 20</td>
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<td>-</td>
<td>-</td>
<td>-</td>
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<td>7</td>
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<td>3</td>
<td>11</td>
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<tr>
<td>31 - 35</td>
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<td>6</td>
<td>6</td>
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<td>18</td>
<td>2</td>
<td>1</td>
<td>-</td>
<td>6</td>
<td>9</td>
<td>27</td>
</tr>
</tbody>
</table>
## A Four State Utilization Study

### AGE GROUP (in years)

<table>
<thead>
<tr>
<th>AGE GROUP</th>
<th>Guj</th>
<th>Ori</th>
<th>Raj</th>
<th>TN</th>
<th>Total</th>
<th>Guj</th>
<th>Ori</th>
<th>Raj</th>
<th>TN</th>
<th>Total</th>
<th>Grand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>41 - 45</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>8</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>46 +</td>
<td>3</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>14</td>
<td>13</td>
<td>13</td>
<td>16</td>
<td>56</td>
<td>14</td>
<td>18</td>
<td>12</td>
<td>22</td>
<td>66</td>
<td>122</td>
</tr>
</tbody>
</table>

### EDUCATION

<table>
<thead>
<tr>
<th>Educational Level</th>
<th>Guj</th>
<th>Ori</th>
<th>Raj</th>
<th>TN</th>
<th>Total</th>
<th>Guj</th>
<th>Ori</th>
<th>Raj</th>
<th>TN</th>
<th>Total</th>
<th>Grand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illiterate</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>1</td>
<td>2</td>
<td>-</td>
<td>1</td>
<td>2</td>
<td>7</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Upto 3rd</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>4th to 6th</td>
<td>-</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>7</td>
<td>-</td>
<td>6</td>
<td>1</td>
<td>7</td>
<td>14</td>
<td>21</td>
</tr>
<tr>
<td>7th to 9th</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>6</td>
<td>16</td>
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<td>2</td>
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<td>28</td>
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<td>Upto 10th</td>
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<td>4</td>
<td>16</td>
<td>5</td>
<td>7</td>
<td>2</td>
<td>5</td>
<td>19</td>
<td>35</td>
</tr>
<tr>
<td>Upto 12th</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>-</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>-</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Graduation</td>
<td>-</td>
<td>-</td>
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<td>2</td>
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<td>3</td>
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<td>-</td>
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<td>-</td>
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<td>-</td>
<td>1</td>
<td>-</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>14</td>
<td>13</td>
<td>13</td>
<td>16</td>
<td>56</td>
<td>14</td>
<td>18</td>
<td>12</td>
<td>22</td>
<td>66</td>
<td>122</td>
</tr>
</tbody>
</table>

### OCCUPATION

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Guj</th>
<th>Ori</th>
<th>Raj</th>
<th>TN</th>
<th>Total</th>
<th>Guj</th>
<th>Ori</th>
<th>Raj</th>
<th>TN</th>
<th>Total</th>
<th>Grand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed (includes women homemakers)</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>-</td>
<td>6</td>
<td>3</td>
<td>9</td>
<td>6</td>
<td>4</td>
<td>22</td>
<td>28</td>
</tr>
<tr>
<td><strong>Service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jobs held with the SLN/ DLN (PC*, DPC**, ORW***, Counsellor)</td>
<td>5</td>
<td>4</td>
<td>8</td>
<td>-</td>
<td>17</td>
<td>8</td>
<td>6</td>
<td>6</td>
<td>2</td>
<td>22</td>
<td>39</td>
</tr>
<tr>
<td>Link workers</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Others (Clerical work, Courier delivery)</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>3</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Self Employed (fruit/clothes vendor, paan shop, etc)</td>
<td>-</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td><strong>Unorganised Sector</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Skilled work</strong> (Electrician, diamond polish, autodriver, plumber, painter, carpenter, tailoring embroidery etc)</td>
<td>6</td>
<td>3</td>
<td>-</td>
<td>4</td>
<td>13</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>
| ![A Four State Utilization Study](image)
As per the data above, women participants (N = 66) outnumbered the men participants (N = 56) in the FGDs. Majority women were in the age group 26 to 35 years and men in the age group 31 to 40 years. Most participants (both men and women) had some level of schooling although percentage of illiterate women exceeded the men participants. Approximately 29 percent of the participants (including men and women) had completed matriculation.

Figure 1: Profile of FGD participants (age group wise)
### Socio-demographic profile of the FGD participants (Men & Women)

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illiterate</td>
<td>3.57%</td>
<td>15.15%</td>
</tr>
<tr>
<td>Upto 3rd</td>
<td>7.14%</td>
<td>4.55%</td>
</tr>
<tr>
<td>4th to 6th</td>
<td>12.50%</td>
<td>21.21%</td>
</tr>
<tr>
<td>7th to 9th</td>
<td>28.57%</td>
<td>12.50%</td>
</tr>
<tr>
<td>Upto 1oth</td>
<td>28.57%</td>
<td>10.71%</td>
</tr>
<tr>
<td>Upto 12th</td>
<td>6.06%</td>
<td>4.55%</td>
</tr>
<tr>
<td>Graduation</td>
<td>21.21%</td>
<td>28.57%</td>
</tr>
<tr>
<td>Post graduation</td>
<td>28.79%</td>
<td>7.14%</td>
</tr>
</tbody>
</table>

### Profile of FGD participants (age group wise)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>3.57%</td>
<td>15.15%</td>
</tr>
<tr>
<td>25-30</td>
<td>7.14%</td>
<td>4.55%</td>
</tr>
<tr>
<td>31-35</td>
<td>12.50%</td>
<td>21.21%</td>
</tr>
<tr>
<td>36-40</td>
<td>28.57%</td>
<td>12.50%</td>
</tr>
<tr>
<td>41-45</td>
<td>28.57%</td>
<td>10.71%</td>
</tr>
<tr>
<td>46-50</td>
<td>6.06%</td>
<td>4.55%</td>
</tr>
<tr>
<td>51-55</td>
<td>21.21%</td>
<td>28.57%</td>
</tr>
<tr>
<td>56-60</td>
<td>28.79%</td>
<td>7.14%</td>
</tr>
<tr>
<td>61-65</td>
<td>10.71%</td>
<td>6.06%</td>
</tr>
<tr>
<td>66-70</td>
<td>3.57%</td>
<td>3.57%</td>
</tr>
</tbody>
</table>

### Profile of FGD participants (occupation wise)

- **Unemployed (includes women homemakers)**: 23%
- **Job held with the SLN/DLN (PC*, DPC*, ORW***, Counsellor)**: 23%
- **Link Workers**: 16%
- **Others (Clerical work, Courier delivery)**: 15%
- **Self-Employed (fruit/clothes vendor, paan shop etc)**: 8%
- **3%***
- **3%***

---

*Figure 2: Profile of FGD participants (age group wise)*

*Figure 3: Profile of FGD participants (occupation wise)*
A significant section, that is, 32 percent of the participants was occupying different positions in the state or district level positive people's networks. Approximately 30 percent of the participants were part of the unorganised sector (engaged in both skilled and non-skilled work). Out of the 23 percent unemployed, 18 percent comprised of women and 5 percent men, indicating that more men were playing the role of providers as compared to women.

The non-users FGD in Gujarat had one FSW, IDU and MSM participant each, who were also engaged in outreach work in their community. Gujarat SLN was perhaps one of the progressive networks that had extended their membership to the marginalised sections who were thus well represented in the FGDs.

### Table 2: FGD participant's profile (district wise)

<table>
<thead>
<tr>
<th>District Coverage</th>
<th>Gujarat</th>
<th>Orissa</th>
<th>Rajasthan</th>
<th>Tamil Nadu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users women FGD</td>
<td>Surat, Bharuch</td>
<td>Bhubaneshwar</td>
<td>Jaipur, Alwar, Bharatpur, Jalore, Dholpur, Ajmer Jhunjhunu</td>
<td>Tiruvannamalai</td>
</tr>
<tr>
<td>Users men FGD</td>
<td>Surat, Navsari Bharuch</td>
<td>Khurda</td>
<td>Jaipur, Dholpur, Jhunjhunu, Nagaur, Bharatpur, Tonk</td>
<td>Dindigul</td>
</tr>
<tr>
<td>Non-users FGD</td>
<td>Surat, Bharuch</td>
<td>Bhubaneshwar</td>
<td>Jaipur, Bharatpur, Nagaur, Udaipur</td>
<td>Chennai</td>
</tr>
</tbody>
</table>

The FGDs were conducted in the premises of the state or district level network’s office in the respective states. Hence, majority of the participants hailed from the same district as the SLN/DLN office and the neighbouring districts.

### Table 3: Profile of key informants

<table>
<thead>
<tr>
<th>Key Informants</th>
<th>PPN</th>
<th>NGO</th>
<th>SACS</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gujarati</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Orissa</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
<td>9</td>
<td>6</td>
<td>25</td>
</tr>
</tbody>
</table>

They key informants from the positive people’s networks comprised of members occupying positions of leadership in the network. The aim was to capture the leadership perspective on social protection for PLHIVs. The NGO key informants too included programme leaders who were involved in HIV mainstreaming activities or reaching social protection to PLHIVs in the State. The key informants from SACS were mainly mainstreaming officials. In Gujarat, the GIPA coordinator who is positioned in GSACS was also interviewed. The GIPA coordinator in Orissa was the point person contact in the State who played an active role in organising the FGDs and identifying key informants.
Social protection schemes (both centrally and state sponsored) currently accessed by PLHIV in the four states of Gujarat, Orissa, Rajasthan and Tamil Nadu.

The following table summarises the types of schemes currently accessed by PLHIV along with the entitlements they offered.

**Table 4: Types of social protection schemes accessed by PLHIV in four states of India**

<table>
<thead>
<tr>
<th>Type of Scheme*</th>
<th>Gujarat</th>
<th>Orissa</th>
<th>Rajasthan</th>
<th>Tamil Nadu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel concession or assistance</td>
<td>Jatan project reimburses public transport travel to ART centre</td>
<td>Range of `75 to 200 – travel reimbursement to ART centre through IRCS</td>
<td>75 percent bus travel concession through State Road transport to ART centre</td>
<td>50 percent railway travel concession</td>
</tr>
<tr>
<td>Pension</td>
<td>`500 per month – widow pension</td>
<td>`200 per month – old age pension</td>
<td>`500 per month – widow pension</td>
<td>`500 per month – widow pension</td>
</tr>
<tr>
<td>Food and Nutrition</td>
<td><code>500 per month – Tabibi Sahay for those on ART drugs 35 kgs wheat flour at </code>2 per kg (AAY) Bal bhog yojana through ICDS – for children</td>
<td>35 kgs wheat at `2 per kg (AAY) Nutrition for children through ICDS</td>
<td>35 kgs wheat at `2 per kg (AAY) Nutrition for children through ICDS</td>
<td>20 kgs rice at `1 per kg (PDS) Nutrition for children through ICDS</td>
</tr>
<tr>
<td>Wage/self employment</td>
<td>`10,000 in one year – NREGA – in rural areas Loan for micro-enterprise through Ghar-divda scheme for SC/STs Initiation of SHGs</td>
<td>`10,000 in one year – NREGA – in rural areas Loan for micro-enterprise through SJSRY</td>
<td>`10,000 in one year – NREGA – in rural areas Loan for micro-enterprise through TAHDCO scheme for SC/STs PLHIV exclusive SHGs to create a revolving fund through SGSY</td>
<td>`10,000 in one year – NREGA – in rural areas</td>
</tr>
<tr>
<td>Type of Scheme*</td>
<td>Gujarat</td>
<td>Orissa</td>
<td>Rajasthan</td>
<td>Tamil Nadu</td>
</tr>
<tr>
<td>----------------</td>
<td>---------</td>
<td>--------</td>
<td>-----------</td>
<td>------------</td>
</tr>
</tbody>
</table>
| **Health**     | Free first line ART treatment  
` 1,000 as one time grant for institutional delivery in JSY | Free first line ART treatment  
` 1,000 as one time grant for institutional delivery in JSY | Free first line ART treatment  
` 1,000 as one time grant for institutional delivery in JSY | Free first line ART treatment  
` 6,000 as one time grant for institutional delivery in JSY |
| **Education of children** | `80 per month per child as part of widow pension  
` 1,000 per month to guardians of AIDS orphans/destitute children – **Palak Mata Pita Scheme** | - | ` 500 (below age 5) or ` 675 per month per child – **Palanhar Yojana** for CABA  
` 2000 per child – annual payment for school uniform/books | ` 3,000 – 5,000 per annum for orphans and vulnerable children – **OVC Trust** |
| **Housing**    | `45,000/- as one time grant for building house in rural areas – **IAY**  
Upto `35,000/- as one time grant for constructing a house on one’s own land – **Mo Kudiya Scheme** | `45,000/- as one time grant for building house in rural areas – **IAY** | `45,000/- as one time grant for building house in rural areas – **IAY** | `45,000/- as one time grant for building house in rural areas – **IAY** | **Kalaigner Veetu Vasadi** – a housing scheme to convert **kaccha** houses into **pucca** houses through surveys conducted by Gram Panchayat and BDO. |
<table>
<thead>
<tr>
<th>Type of Scheme*</th>
<th>Gujarat</th>
<th>Orissa</th>
<th>Rajasthan</th>
<th>Tamil Nadu</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Crisis assistance</strong></td>
<td>`10,000/- NFBS - one time grant to BPL widows who lose their breadwinner (known as ‘Sankat Mochan Yojana’ in Gujarat</td>
<td>`10,000/- NFBS - one time grant to BPL widows who lose their breadwinner</td>
<td>`10,000/- NFBS - one time grant to BPL widows who lose their breadwinner</td>
<td>`10,000/- NFBS - one time grant to BPL widows who lose their breadwinner</td>
</tr>
<tr>
<td></td>
<td>`10,000/- as one time grant through the Chief Minister’s Relief Fund for needy and indigent persons</td>
<td></td>
<td></td>
<td>`10,000/- as one time grant through the Distress Relief Scheme to legal heirs of the deceased breadwinner.</td>
</tr>
<tr>
<td></td>
<td>`2,000/- as funeral expenses to the HIV affected family.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Legal aid</strong></td>
<td>Legal aid services through the positive people’s networks.</td>
<td>Legal aid services by the Human Rights Law Network (HRLN)</td>
<td>Legal aid through Rajasthan State Legal Services Authority for WLHIV</td>
<td>Legal aid clinics to provide free legal advice to PLHIV in several districts</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Legal aid services by the Human Rights Law Network (HRLN)</td>
<td></td>
</tr>
</tbody>
</table>

(*Refer to Annexure 1 for details about the eligibility criteria, process of applying for the different schemes and the implementing agency*)

Although the central and the respective state governments have several more schemes, there was evidence of uptake of select schemes by persons living with HIV or affected by HIV. The study found an evidence of more than 25 different types of schemes (inclusive of state specific and central schemes) that cover broad categories, namely, travel concession, pension, food and nutrition, wage/self employment, health, education of children, housing, crisis assistance and legal aid.

The uptake of schemes was the outcome of the mainstreaming initiatives of the respective SACS in collaboration with the positive people’s networks and NGOs in the state. While there were similarities in the type of mainstream schemes being tapped, there existed state level variations in the focus on specific schemes. Following is a brief state-wise description of the same:

**Case of Gujarat**

Gujarat had focused on schemes like Tabibi Sahay, reimbursement of travel to ART centers through the Jatan Project of the Gujarat State Government, widow pension scheme, Palak Mata Pita Scheme for CABA, Antyodaya Anna Yojana (AAY) and livelihood schemes through NREGA and self-help groups for PLHIV within the State.
Case of Orissa
In Orissa, the most accessed scheme was the pension scheme under the Madhu Babu Pension Scheme. Other schemes utilised by PLHIV were the Mo Kudiya housing scheme, AAY and National Family Benefit scheme (NFBS). PLHIV also availed of travel reimbursements through the Indian Red Cross Society (IRCS) although the disbursement channels varied across districts.

Case of Rajasthan
PLHIV in Rajasthan focused on the access of the following five schemes: widow pension, Palanhar yojana, AAY, travel concession (bus pass) for ART treatment and BPL card to receive free medical treatment under the Mukhya Mantri Jeevan Raksha Kosh (MMJRK) scheme. There was evidence of use of other schemes like NREGA, NFBS and initiation of SHGs, but the primary focus continued to be the above five schemes.

Case of Tamil Nadu
Widow pension was the most commonly used scheme among women in Tamil Nadu. Many had availed schemes like NREGA and Indira Awas Yojana, but, this was facilitated by the BPL status of the HIV household and not necessarily the HIV status. Other livelihood options came through loans provided by Tamil Nadu Adi Dravida Housing Development Corporation (TAHDCO) for self employment like goat/cow rearing. Railway travel concession, a hitherto popular scheme saw a reduced uptake after link ART centres opened up in each district in Tamil Nadu as buses were preferred for short distance travel. The state health insurance scheme known as ‘Kalaignar Kappettu thittam’, recently introduced for PLHIV enabled them to receive free investigation facilities in government hospitals. STAR health insurance was promoted by the INP plus and was also availed by many.

Facilitating factors in the uptake of social protection schemes by PLHIV
As per the study, following factors were responsible for facilitating the uptake of social protection schemes by PLHIV:

- Synergy between the positive people’s networks, NGOs and SACS.
- Cooperative and sensitive officials in the government machinery – role of other significant stakeholders.
- Assertive stand by users, networks of persons living with HIV and NGOs to demand services.
- Awareness and knowledge about social protection schemes.
- Governance related aspects.

Synergy between the networks of persons living with HIV, NGOs and SACS
Uptake of social protection schemes by PLHIV was an outcome of collaborative and sustained efforts of the networks of persons living with HIV, NGOs and SACS. Networks of persons living with HIV and NGOs represented positive people’s voices and the SACS as a competent authority had been able to reach these voices to the different government Ministries and Departments to advocate for special provisions for PLHIV. The facilitative role of each stakeholder is described below:
Facilitative role of the positive people’s networks (PPNs)
As part of NACP – III, NACO had supported Indian Network for Positive People (INP+) in establishing and strengthening 22 state level networks (SLNs) and 221 district level networks (DLNs) of PLHIV for mobilising communities and ensuring their access to services, such as ART centres, community care centres and drop-in centres (NACO, 2010). The facilitative role of the positive people’s networks in the uptake of schemes by PLHIV came through the following initiatives:
- Advocacy for special provisions for PLHIV in mainstream schemes
- Addressing constraints by reviewing implementation issues
- Assistance in applying for the schemes

Advocacy for special provisions for PLHIV in mainstream schemes
PLHIV found themselves excluded from social protection schemes because the eligibility criteria disenabled their participation. For example, the widow pension in Rajasthan was open to widows above the age of 40 years. But, HIV widows were much younger in age. Similarly, schemes like Tabibi Sahay (Gujarat) and bus travel concession (Rajasthan) was targeted to persons with disability or suffering from cancer. The Madhu Babu Pension scheme (MBPS) in Orissa was meant for widows, elderly and the disabled only.

The positive people’s networks in joint collaboration with the respective SACS successfully advocated for special provisions in mainstream schemes to include PLHIV in the state. This advocacy helped to bring about a relaxation in the eligibility criteria targeted to PLHIV thereby expanding the coverage of schemes like widow pension, bus travel concession, Palanhar Yojana to all CABA, Mukhya Mantri Jeevan Raksha Kosh (Rajasthan), MBPS (Orissa), Palak Mata Pita (Gujarat) and so on. (For more information, refer to Section 3.d on Successful strategies: special provisions in mainstream schemes)

Addressing constraints by reviewing implementation issues
The advocacy role of networks of persons living with HIV did not remain restricted to allotment of special provisions in mainstream schemes; it also extended to the review of constraints faced by community members in accessing the schemes. This review process was helpful to address the barriers and make the scheme more suitable to the local needs of the users. For example, a network of persons living with HIV in Tamil Nadu experienced that it was not viable to have a SHG with minimum 20 PLHIV members in a single village. Hence they mooted for a relaxation in this rule by according the status of a special group, similar to SHGs by SC/ST and disabled persons (refer quote).

“In Virudinaka Vilipuram we tried getting 20 women together to do some business, but it did not work. So now we are trying it in groups of 5-7 women because these women themselves are providing a loan of 3 lakhs rupees. This much money only a small group can manage. Ordinary SHG will get the loan and use it for personal benefit not for business benefit.”

– a CBO respondent from Tamil Nadu
Similarly, end users of the bus travel concession in Rajasthan were unable to receive the bus pass because the Rajasthan State Roadways Travel Corporation (RSRTC) insisted on a list of all PLHIV in the state from RSACS to issue the bus pass to genuine users. RSACS was unable to provide such a list for two reasons, first, that as per the directives of the Supreme Court, a PLHIV’s status must be kept confidential and second, that such lists were maintained only by the ART centers. The network of persons living with HIV in Rajasthan reported this barrier to RSACS and RSRTC following which a decision was made to have a panel of 3 doctors to certify that the applicant was indeed HIV positive and in need of ART treatment.

In another instance from Tamil Nadu, the age criterion for widow was believed to be 45 years which prevented many from applying. When the networks and SACS approached the social welfare department, they discovered that the age criterion was relaxed to 18 years in 1990 itself. They arranged to send copies of the GO to all the district collectors and other networks and NGOs to facilitate the uptake of widow pension scheme.

**Assistance in applying for schemes**

Most of the participants reported complete lack of knowledge about the schemes prior to registering with the district level network. The DLN staff were the foot soldiers of the networks who created awareness about social protection schemes among their fellow members, enabled them to fill up the requisite forms and procure relevant documents. They accompanied their fellow DLN members to the relevant government department to ensure a smooth application process. In some instances, they used their rapport with the government officials to enable speedy action.

**Some limitations in the role of PPNs due to differential perspectives and impact on social protection for PLHIV**

The network of persons living with HIV, by virtue of representing community’s voices, had gained a formidable position which significantly helped influence policy change in the favour of PLHIV. The network of persons living with HIV clout also helped certain participants to procure relevant documents, avoid bribes and address stigma and discrimination at the service delivery points. However, there was a downside to this facilitative role of network of persons living with HIV because in many places, instead of a unified state level network, there were parallel district level networks that operated in their fiefdoms and were in conflict with other networks of the state due to differences in perspectives and ideology.

This inter-network conflict diluted concerted action in the advocacy for social protection schemes. An example is the filing of a PIL by one network of persons living with HIV against another with respect to the roll-out of a programme by the latter. Similarly, the lines of divide between the women’s and men’s networks in Tamil Nadu ran deep. Women’s groups were against the provision of social protection for men since they were traditionally in a stronger position in the patriarchal society whereas the women were more vulnerable and had received HIV from their spouses.
Facilitative role of NGOs

Advocacy, building linkages, training and follow-up work done by NGOs with a professional rigour and credibility and rapport with the government department helped a large number of PLHIV to access the social protection schemes. For example, a NGO in Tamil Nadu had organised PLHIV into SHGs, assisted in opening bank accounts and availing income generating activities through SGSY.

In many cases, the NGOs complemented the role of network of persons living with HIV in their state. For example, the mainstreaming resource units (MRUs) of UNDP in Orissa and Rajasthan, while conducting HIV sensitisation workshops for government department officials, included a discussion on the provisions and significance of social protection schemes for PLHIV, relevant to their department. PLHIV, representing the network were also invited to discuss the work done by their network of persons living with HIV on social protection schemes. These workshops intended to create an enabling environment for PLHIV while accessing social protection schemes. A similar strategy was adopted through the positive speaker’s bureau (PSB) in Gujarat.

In Tamil Nadu, the NGOs and the network of persons living with HIV also paid the premium for the Star health insurance scheme for those PLHIV who could not afford to contribute that amount.

Facilitative role of State AIDS Control Societies (SACS)

The State AIDS Control Societies had played a significant role in liaising with the concerned government departments and units by initiating suitable mainstreaming strategies, in all the four states. This was achieved in partnership with network of persons living with HIV and NGOs in their State.

Use of studies to build a case for special provisions for PLHIV

Proposals that explained the specific needs of PLHIV, the special provisions being sought and the fiscal burden it would accrue to the government department was one of the advocacy strategies of the mainstreaming officials of the SACS. For example, in Tamil Nadu, the SACS, advocated for special nutrition packets for women and transgenders on ART (see quote below).

“In our proposal for special nutrition exclusively for women/transgenders on ART, we suggested for TANSACS to submit an indent to the social welfare department to place an order to the PDS. PDS will prepare nutrition packets that contain fortified atta and two kinds of daal and rice together. We had 2 options, PDS to package it and give it to the ART centers for distribution. But ART centers could not stock these packets for problem of rats. So we went by the second option of coupons to be redeemed at the Amudam stores. This file is still pending at the social welfare department”.

— key informant from Tamil Nadu
Should this proposal be executed, women and transgenders in Tamil Nadu will benefit greatly since nutrition is a primary concern, especially when one is on ART.

**Fostering empowerment of the positive people’s networks**

Gujarat SACS aimed to empower the state level network (SLN), that is, Gujarat State Network for Positive People (GSNP+) by helping them to prepare a proposal for the Jatan project and present the same before the State Health Minister. GSACS had promoted the SLN to implement the Jeevandep project in 20 districts of Gujarat. This project employed a project coordinator (a professional social worker) and two PLHIV communicators (one male and one female) who received training in social protection schemes. These communicators played a crucial role in helping fellow PLHIV apply for different social protection schemes in Gujarat.

**Initiating relevant schemes for PLHIV**

Tamil Nadu SACS had played a crucial role in developing the Other Vulnerable Children Trust (OVCT) which is a scheme to provide financial assistance to AIDS orphans and vulnerable children. TANSACS was able to leverage a corpus fund of ` 5 crores from the State government. The interest earned out of this corpus fund was used to provide a cash transfer of ` 3,000 to 5,000 per annum to CABA to meet their educational and nutritional needs. The district administration was used for the disbursal of benefit to the selected applicants.

Similarly, Orissa SACS had played an instrumental role in the inclusion of all PLHIV in the state in Madhu Babu Pension Scheme which was targeted at persons with disability, elderly and widows. The mainstreaming unit at OSACS also monitored the progress of MBPS and reported to the Chief Minister of State, if necessary.

**Cooperative and sensitive officials in the government machinery – role of other significant stakeholders**

**Role of government ministries and departments**

The key government ministries/departments like the Rural Development, Social Justice and Empowerment (SJE), Women and Child Development (WCD), Food and Supplies, Health and Family Welfare, Surface transport and Roadways and so on had responded by amending their schemes to provide coverage to PLHIV. Examples: UNDP project state, Rajasthan, modified the scheme to cover all HIV+ widows irrespective of age. Others are following suit. ii) Government provides free antiretroviral treatment to all persons living with HIV. But, several drop out due to travel costs. Many states now provide free transport to PLHIV. iii) To motivate extended family/community to care for HIV+ orphans, some states give monthly allowance for the care of each child. iv) People below poverty line get an entitlement card for benefits like subsidised food, housing, health care. Several states have offered them to PLHIV; v) Ministry of Labour has removed HIV-exclusion clause from special health insurance scheme for informal sector workers.

Special provisions for PLHIV became a reality due to the proactive role played by the leadership in these government Departments and Ministries.
Role of the District Administration Officials

Officials like the Collector\(^1\), tehsildar\(^2\) and patwari/talathi\(^3\) of the district administration had different roles to play in the access of social protection schemes by PLHIV. For example, the Collector played a crucial role in Indira Awas Yojana in allotting the land patta (small piece of land) in Tamil Nadu, travel reimbursements in Orissa and so on. The patwari or talathi was frequently contacted by PLHIV applicants for procuring the income certificate which was a crucial supporting document in schemes with income slabs as eligibility criteria (for example Palanhar Yojana, widow pension scheme, Palak Mata Pita Yojana, Tabibi Sahay, and so on).

Participants pointed out that Collectors who were sensitive, cooperative and proactive, made a significant difference in allotment and disbursement of social protection schemes. This was attributed to the Collector being part of the District AIDS Advisory Committee that helped to increase sensitivity towards PLHIV. Similarly, a talathi/patwari’s cooperation and guidance was crucial in acquiring documents for application of schemes.

Role of the Panchayati Raj Institutions (PRIs)

The Sarpanch at the village panchayat level was frequently approached by PLHIV for supporting documents (like residence proof) to be attached with the application form. The Sarpanch’s role was also crucial for identification of BPL households in a village which is a significant criterion for most of the social protection schemes. However, some users were wary of coming forward to avail schemes lest the Sarpanch disclose their HIV status to all in the village.

Assertive stand by users, network of persons living with HIV and NGOs to demand services

A corrupt and indifferent service delivery system often led to denial of benefits and services or incomplete receipt of the same. In such cases, assertive stand taken by the users (either individually or collectively) to demand services helped the fulfilment of scheme. The following examples testify the power of users/beneficiaries in holding the service delivery system accountable:

**Proactive stand to receive complete wages in MGNREGA:** Participants from Tamil Nadu

“Some people in our Nagaur district got `35, 38 or 40 only. When they became aware that they are supposed to get `100, they wrote to a letter to the collector who verified the MGNREGA scheme and consequently they began receiving proper wages”.

— woman FGD participant from Rajasthan

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\(^1\) The Collector, is the head of the revenue administration in the district and acts as the co-ordinating officer among all the officers of the government in the district.

\(^2\) Tehsildar is responsible for obtaining taxation revenue for the Tehsil/Taluka.

\(^3\) Talathi or Patwari are village accountants whose duties include maintaining crop and land records of the village, collection of tax revenue and irrigation dues. Amongst the administration, they have the closest connection with the village people. (http://en.wikipedia.org/wiki/Village_accountant)
and Rajasthan shared MGNREGA workers were given ` 80 and sometimes as less as ` 35 as wages and made to sign on ` 100 by the officials at the job site. When end users of this scheme became aware and took a proactive stand against denial of stipulated wages, things were set right, as evident in the quote from Rajasthan (see quote).

**Collective stand against bribe and corruption:** A participants from Gujarat who was a Jeevandeep staff member, shared that she submitted 32 duly filled Tabibi Sahay forms at the social welfare department. The official there offered to ignore eligibility criteria and sanction all the applications if they paid a bribe of ` 200 per form. This participant consulted her fellow members and they all took a collective decision to not pay the bribe even if they stood to lose from the scheme.

Forms of corruption emerged at any point in the service delivery chain. Sustained follow up, grit and determination and assertiveness helped a user reclaim his benefit as evident in the quote below.

**Use of RTI to expose corruption:** An NGO in Orissa used the Right to Information Act to expose the misappropriation of rice allotted to the mid-day meal scheme by a few corrupt officials. This proactive stand contributed to the effective implementation of the scheme.

**Assertion against discrimination:** Women participants from Rajasthan felt inspired by the fearless handling of HIV related discrimination by a bus conductor (refer quote)
Awareness and knowledge about social protection schemes

Based on their experiences of accessing schemes, participants were well versed with information about the application procedure and the supporting documents required for a particular scheme. Higher levels of awareness among certain participants (especially in Gujarat, Rajasthan and Orissa) can be attributed to their role as outreach workers, actively involved in creating awareness about schemes among fellow network members. However, this knowledge about schemes was not global but relegated to schemes that the network of persons living with HIV, NGO and SACS had focused on in their state. For example, participants from Rajasthan had not heard about SGSY as a livelihood scheme or even IAY since it was not on the agenda of their network. Similarly, women users from Orissa were not aware about the provisions of MGNREGA.

Majority participants reported complete ignorance about social protection schemes prior to registering with the network. It is likely that access to the know-how about schemes through membership to the network of persons living with HIV facilitated the uptake of these schemes such that these staff members were among the earlier ones to apply and receive the benefits.

Overall, having detailed knowledge about who to approach and what documents to produce for a scheme enabled users to initiate the right steps with the concerned officials. But, knowledge and awareness about the schemes did not necessarily translate into accessing them because of constraining factors like lack of supporting documents, stigma and discrimination etc. which are covered in detail in the following section on this topic.

Use of IEC to spread awareness about schemes

A positive people’s network in Tamil Nadu had developed a booklet in regional language on different social protection schemes relevant to PLHIV for its fellow members. This was a useful guide to access schemes. Orissa SACS too developed audio visual clips with songs that were aired on radio and television along with other forms of art to spread the message about MBPS and the rights of PLHIV. This significantly helped PLHIV to come forward for the MBP scheme from the remote areas and villages as well.

Governance related aspects

Gol notification for PLHIV in a centrally sponsored scheme

A Gol notification propels the implementing agency (State governments) to extend services to the beneficiary group and aids the latter (positive people’s networks and other stakeholders) to demand services. The central government order in the case of AAY facilitated advocacy by networks and respective SACS with the State governments to issue letters to all officials (upto the district and block level) for providing AAY cards and entitlements to all PLHIV.

Good governance in the district administration

In Gujarat, participants perceived that good governance in the district administration played a major role in facilitating social protection schemes for the poor including IAY.
Public disbursement of the benefit

Another procedure in IAY that benefitted many was the disbursement of the entitlement cheque in public (in Gujarat). Earlier, after the sanction, the cheque went to the Zilla Parishad, then the Taluka, and disbursed at the Panchayat level. But the current practice was to issue the cheques in the lok mela on the basis of the details of the users.

Ease of application procedures

In Tamil Nadu, the procedure for availing the widow pension and old age pension was made easy and quick for the PLHIV. The simplified procedure required the HIV widow to go with her ART card to the Tehsildar who forwarded the same to the Collector. Similarly, for old age pension, facts (like the applicant’s age group, lack of a son to support the family and no property in her name) had to be verified by the Village Administrative Officer (VAO) for speedy process of the application.

Participants from Tamil Nadu reported that officials and staff in the government machinery were fairly sensitive to HIV related issues and did not get ‘shocked’ like before if PLHIV shared their status to access the schemes. This was immensely helpful since applicants/users did not have to fear stigma and discrimination and could openly share their HIV status.

Summary

This section has listed more than 25 different types of schemes (inclusive of state specific and central schemes) based on the evidence of uptake by PLHIV in the four states of Gujarat, Orissa and Tamil Nadu. These schemes cover broad categories, namely, travel concession, pension, food and nutrition, wage/self employment, health, education of children, housing, crisis assistance and legal aid.

The subsection on facilitating factors demonstrates that the positive people’s networks, NGOs and the SACS have been the force behind the uptake of social protection schemes by PLHIV. Each of these stakeholders has a comparative advantage and together their synergy has made access to social protection schemes a reality for PLHIV. Interestingly, different states were able to capitalise on different mainstream schemes thereby indicating a complex interplay of several stakeholders from the State Ministries/Departments, the District Administration and the Panchayati Raj institutions. The dynamic role of individuals/officials occupying these offices

I am a member of Zilla Gram Vikas committee. As a part of good governance the committee meets regularly every month where the collector and the DGO participate. In this meeting all the block officials are asked to report on the number of BPL families in their area. E.g. If they say 250, they are asked, “Out of 250 you were to give Awaas Yojana to 100, so what is the target you have achieved and how many applications have come in?”

– a NGO representative in Gujarat
either facilitated or constrained the uptake of schemes. Sensitive, cooperative and proactive individuals significantly contributed in the form of approval for special provisions in mainstream schemes and enabled easy disbursal of benefits.

The assertive stand taken by users, networks and NGOs (either individually or collectively) against an indifferent service delivery system, discriminatory acts of service providers and issues relating to corruption and bribes has been significant in the realisation of rights and entitlements as per the social protection schemes.

Awareness about social protection schemes had not necessarily led to their access because of its dependency on several other factors. But awareness about schemes along with details about the application procedures was a pre-condition to initiate the right steps in this direction. This is a signal for mainstreaming initiatives to focus on spreading adequate knowledge about social protection schemes among the target populations in order to scale up the utilisation of such schemes.
Constraining factors in the uptake of social protection schemes by PLHIVs

PLHIV face several challenges in accessing the social protection schemes. These can be categorized under issues relating to procedures, governance, HIV related stigma and discrimination, weaknesses in some schemes and the scope.

Procedural issues

Several procedural issues, stemming largely from programme design, emerged as constraining factors in accessing social protection schemes. These include restrictive eligibility criteria, cumbersome application procedures, delays in processing of application forms or receipt of benefits and opportunity costs in applying for the schemes or collecting the benefit. Each of these points is discussed below:

Restrictive eligibility criteria

The eligibility criteria form the framework for targeting the poor and vulnerable groups as beneficiaries of the social protection programme. These criteria often relate to the age of the applicant, annual income, place of residence, caste and so on. The significance of eligibility criteria is not contested, but, when they have rigid boundaries, they either exclude the vulnerable groups or inadvertently encourage people to resort to submitting false documents as evidence to gain entry into the scheme which further reduces coverage.

The following scheme wise examples throw light on the same:

Widow pension

In Gujarat, the criterion of submitting the widow pension application within 2 years of the husband’s death was a huge barrier for women. This is because the social norms of reduced mobility after the spouse’s death or lack of knowledge about the scheme prevented the widows from applying within the specified period. The other eligibility criterion about the annual income not exceeding Rs. 2400/- was also an impediment. Many women possibly earned more than

“For widow pension then they want an income certificate of Rs. 2400 per year only. Is it possible to run a household on a monthly income of Rs. 200? The light bill that I had submitted along with my application was of Rs. 300. The social welfare department questioned me that, if you are showing an income of Rs. 200 per month than how can you afford to pay a light bill of Rs. 300? We had an argument and I explained that I have three children and my brothers and others are helping so I can run my house. After facing a lot of obstacles and putting forth a lot of requests, my application was passed”.

- a woman user in Gujarat
this amount even by taking up odd jobs on daily wage basis. Income criteria of Rs. 200 a month seemed unrealistic in the current context. Women felt forced to produce false certificates in order to avail the scheme.

Other eligibility criteria for widow pension in Gujarat, like not having a child over 12 years of age and having no property or land in one’s name also created barriers to access (refer quote).

In Rajasthan too, widows were required to be above the age of 40 years as chances of remarriage after this age were less! Also, if she had a son above 25 years, she could not apply since the son was socially responsible for her well being. These criteria were however waived off due to sustained advocacy efforts of the networks and SACS in the state. In Orissa, only one scheme per PLHIV was permitted. If a PLHIV was receiving widow pension, then she could not avail of Antyodaya Anna Yojana and vice versa. Economising resources could have possibly guided this criterion, but WLHIVs were at a disadvantage because both pension and nutrition were significant to their needs.

Tabibi Sahay

Tabibi Sahay of Gujarat had the following eligibility criteria that included or excluded a PLHIV beneficiary:

- The applicant should be a resident of Gujarat since 1978. In other words, the applicant should be a domicile resident of Gujarat for minimum 32 years.
- The annual income of the applicant should not be more than Rs. 15,977 per annum if hailing from rural areas, and not more than Rs. 21,205 per annum, if hailing from urban settings.
- The applicant should not be from the SC/ST category
- The applicant should be socially and economically backward
- The applicant should be on ART drugs
- If a PLHIV has already been accessing this scheme for TB or cancer or leprosy, then application for HIV was rendered inapplicable.

Each eligibility criterion posed a challenge in accessing Tabibi Sahay.

Minimum 32 years domicile residents: this criterion excluded many applicants who had not lived for minimum 32 years in Gujarat. Few participants shared their anguish over rejection of their application after having collected all other supporting documents (ration card, voter ID card, etc) only to be told about the 32 years clause.

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"When the talathi checks the record, he will say that the person owns land. In reality the land is mortgaged with a zamindar (moneylender). But since the person’s name appears on the record she won’t get benefit of the scheme."

- key informant from NGO in Gujarat

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Tabibi Sahay offers a cash transfer of 500 per month to enable users to buy nutritious food.
Due to the influx of PLHIVs from neighbouring states to Gujarat for ART treatment, the state government used this clause to prioritise natives of the state or migrants residing prior to 1979 for this benefit. The state level network had been pushing for a change in this clause and currently this criterion was being considered for revision by the Department for Social Justice and Empowerment.

**Annual income criteria:** To keep a check on middle/higher income households from applying for this scheme, economic boundaries had been defined for the applicants wherein they were expected to attach an income certificate not exceeding the specified amount. Although such ‘checks’ were well intended, they did not meet their purpose if the income slabs were not updated in keeping with present times.

“We have sensitized the mamletdar and so when we tell him we need the income certificate of Rs. 20,000 per annum, he gives it to us. In Rs. 20,000 per year, you can’t even survive in a room in Surat. These are unrealistic figures, so we get it made, because otherwise we won’t get the benefit of the scheme.”

– men user FGD participants from Surat, Gujarat

**Caste exclusion:** This scheme was targeted for socially and economically backward PLHIVs, that is, those from the OBC community. SC/STs and upper caste PLHIVs having income more than Rs. 15 to 20,000 per annum could not apply. Participants mentioned that the rationale for not including SC/STs was that they received benefits through many other target schemes. However, the SLN had written to the Department of SJE to include PLHIVs from the SC/ST category as well.

**Palak Mata Pita Yojana**

Palak Mata Pita Yojana\(^2\) required guardians of Children affected by AIDS (CABA) to have an income not less than Rs. 60,000 per annum. Due to this criterion, users with a lesser income prepared a false income certificate to avail the scheme. Participants discussed that although this criterion was framed because a poor household was more likely to spend the money for expenses other than the beneficiary child’s needs, in reality, a household with that kind of income would not depend on this scheme. Further, this income certificate came in the way of accessing Tabibi Sahay where guardians were expected to have an income not exceeding Rs. 20,000 per annum.

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\(^2\) Palak Mata Pita Yojana is a scheme of Gujarat scheme that offers a conditional cash transfer of 1000 per month to guardians of CABA to take care of their educational and nutritional needs.
A key informant in leadership position explained that their sustained advocacy efforts had led to the inclusion of PLHIVs in the mainstream scheme. They were trying to study the implementation issues at the field level to push for suitable changes.

**Mo Kudiya housing scheme (Orissa)**
The criterion of having one’s own piece of land to receive a onetime grant for construction of a house was a barrier for accessing Mo Kudiya housing scheme, especially for the landless poor, widows, single and destitute women among PLHIVs. This was difficult for widows, if estranged from the marital family, because the title to the land often belonged to the in-laws.

**Star health insurance**
The SLN in Gujarat found the criterion of minimum 200 members’ group difficult to meet with as several members preferred the free health coverage through alternate health care services or settings.

**Cumbersome application procedures**
The application procedures often required the applicant to submit a duly filled form along with several supporting documents like:

- Proof of age (birth certificate/ school leaving certificate/ doctor’s letter specifying the age/ affidavit),
- Identity proof (voter’s ID card),
- Residence proof (ration card),
- Domicile certificate,
- Proof of HIV status (in cases of schemes with special provisions for PLHIVs), annual income certificate,
- Death certificate of the deceased spouse (in case of widow pension and NFBS),
- Proof of bank/ post office account (for account transfer of cash),
- School bonafide certificate (for cash transfer schemes related to education of children) and so on.

There was no uniformity observed in the types of supporting documents admissible across schemes and the variations persisted across states and even within districts in a state. Participants often did not have such documentary evidences in place and had to run pillar to post to procure them from different officials in the district administration, PRIs, municipalities in semi-urban or urban areas or local corporators. In other instances they went to lawyers/ advocates/ notary to prepare affidavits in lieu of the required documentary proofs.

Participants felt constrained by this cumbersome application procedure if they could not procure all the documents, experienced stigma and discrimination while getting the documents prepared or incurred heavy expenses for photocopying, buy stamp papers for affidavit, advocate fees or travel expenses to prepare the documents and submit the complete application form. Those who could not cope with this procedure left the attempt to apply mid-way.

A few examples are cited below to highlight people’s experiences with regard to cumbersome application procedures:
Income certificate is a crucial documentary evidence for schemes targeted to the poor wherein the applicant’s income should not exceed a given figure to be eligible for the scheme. A few users shared that they had to depend on the whims of the patwari/ talathi for the income certificate (refer quote). A participant from Rajasthan shared that if one’s relations with the patwari were strained, then the person was ‘damned’ because the patwari could refuse to make the document or even reveal the HIV status of the applicant to all.

For old age pension, proof of age was vital to be eligible to the scheme. Many elderly from the HIV affected families did not have the necessary certificates for proof of age. They had to stand in crowded corridors of a hospital to get the requisite age certificate from the doctors of the civil hospital, despite their fragile condition.

For railway travel concession too, apart from the fact that train routes were limited and unsuitable, the process of getting a letter from the ART centre and getting the concession form signed from the railway authority, for every travel, was cumbersome and time consuming (as shared by participants from Gujarat and Orissa). This prevented them from accessing the scheme.

Short term migrants to other cities were denied of PDS or AAY as their ration cards were not accepted in other cities. Women were unable to procure the deceased spouse’s death certificate or ration from the in-laws if estranged from them. As an alternative, women submitted an affidavit or negotiated with the in-laws to share the benefit amount in order to get the death certificate or requested the government doctors to provide such letters.

“It took me some 6 to 7 months to get NFBS. I had make atleast 2 to 4 rounds to get the form. They repeatedly asked me to bring the original death certificate. To get the income certificate, it took about a month. It took another four months after submitting the form. I would call the up the official repeatedly and enquire why he hasn’t visited my house for verification. He would answer that he has a lot of work. Then one day I went there and asked if they want to come at all? Then they came home for verification. After visiting also it took three more months for them to give me the cheque. They told me that it would take time as someone’s signature was still pending. Even after my cheque had come they didn’t give it. They asked for an affidavit stating why my husband died in Mumbai? After giving them that affidavit they gave me my cheque”…

– user FGD women in Gujarat
For some women it took 6-7 months after the death of their husband to receive the benefit of NFBS. In case of a participant in Orissa, it took four years to receive the benefit after her husband’s death. Repeated demand for submitting various documents caused the delay. For example, in one case, a participant was asked to submit birth and school leaving certificates of the husband. It was difficult for many women to fulfill all the requirements especially those who were deserted by their marital family. These delays were further exacerbated if the spouse died outside their hometown, in another city or state (refer quote).

There seemed to be a difference of opinion about accessing the scheme among the officials and the people. In Tamil Nadu, according to one SACS officer, it was easily accessible through the legal aid clinic. However, several of the women participants reported that they had difficulties in procuring all the required certificates and had to pay bribe. The net amount received turned out to be very low after factoring the opportunity costs (of preparing the documents, travel fare, bribes, etc).

Similarly, cost of extensive paperwork and travel by PLHIVs as well as restrictions on women regarding frequent travel to the city were barriers to accessing legal aid. Cases were not followed up and remained unresolved.

**Delays in receiving the entitlements**

Participants lamented over the issue of delay in receiving the benefits under various schemes. These delays were either due to lack of grant from the central or state government or due to teething problems in newer projects like the MBPS (in Orissa) or Jatan in Gujarat. While few participants felt that a quarterly transfer of benefits was useful since one received a larger amount at one go, many others felt that a regular monthly cash transfer was preferred to meet with the monthly expenses. Following are some scheme wise example to explain this issue:

Many participants complained about the delay in processing of applications in **Madhu Babu Pension scheme** in Orissa. On an average the delay was of 6 months to 2 years. The recently identified PLHIVs got the pension comparatively easily as compared to those who were detected before 2008. The major reason provided by the SACS representative was the shortage of human power to handle the paper work of the increasing number of applications. There was also delay on the part of the ICTC, due to its heavy workload, in submitting the list of PLHIVs to the Women and Child Development Department every 6 months.

The time lag between applying for the scheme and getting the benefits was 8 to 9 months in Gujarat for the **widow pension**. Such delays and long drawn processes demotivated the applicants who eventually dropped out from applying for the pension. In **Tabibi Sahay** (Gujarat) too, user participants reported the non-receipt of benefit (from April 2010 till the time of data collection in September 2010). They were informed about the lack of grant flow from the State department as the reason for this delay.

In the travel assistance project **Jatan** of Gujarat, a 3 to 4 months delay to receive the travel reimbursement was embarrassing for those who borrowed money to travel to the ART centre hoping to return the money the same evening. These delays created doubts in the integrity of the scheme. GSACS officials viewed these constraints as teething problems in the pilot
phase of the programme since staff needed guidance in maintaining accounts, auditing, and compiling data from all 20 districts undertaken by GSNP+

According to a NGO in Tamil Nadu, it took almost 3-4 years to actually get the house under IAY. In many instances, after 3 or 4 years, the government or Panchayat denied the benefits by claiming that the scheme had changed, furthering the delay and creating uncertainty. In legal aid too, there were a lot of pending cases of PLHIVs, resulting in increase in the burden of the expenses on legal matters. In some cases the time lapse was of more than 5 years.

**Opportunity costs arising out of mode of payment**

Sometimes, the mode of payment brought opportunity costs for users which reduced the net transfer of benefit. For example, in Orissa, the participants had to travel from the ART centre to the network office in Bhubaneshwar to collect the travel reimbursement money which was an additional cost. In certain districts in Orissa, users had to travel to the Collector’s office to collect the travel reimbursement which was not only an added liability, but also led to disclosure of the user’s HIV status.

In Tabibi Sahay of Gujarat, the mode of payment was a money order. Men who were away at work during the day were not available to receive the money order when it arrived. They had to spend additional time and money to collect it later from the post office.

For MBPS in Orissa, there was a demand from the NGOs and PPNs to have a uniform mode of cash transfer, that is, through the bank account of the user (instead of the current cheque payment). But this was a problem, especially in villages where PLHIVs did not have a bank account. As an alternative, if a PLHIV took the entitlement cheque to the Commissioner and told him that he/ she could not afford to open a bank account, he gave a self check in return for their crossed cheque.

**Governance issues**

Problems related to improper implementation of schemes, corruption, bribes and poor quality of services can be attributed to lack of good governance thereby reducing the effectiveness of social protections schemes and constraining users from accessing the schemes.

**Issues related to implementation of schemes**

**Lack of awareness and clarity regarding the scheme at the service delivery point**

When implementing staff at the service delivery points did not receive adequate communication about new policies and government orders regarding different schemes (especially those relating to special provisions for PLHIVs), it led to procedural difficulties to the end users and sometimes even denial of services/ benefits.

For example, participants from Rajasthan shared about the apathy of the bus depot manager who claimed ignorance about directives from RSRTC regarding bus travel concession for PLHIVs. Key informants attributed this difficulty to a lack of communication mechanism to inform staff at the service delivery points (bus depot manager, bus conductor, etc.).
difficulty also led to discriminatory actions like being asked to leave the bus or rebuked in front of all passengers. Similarly, the hospital staff in Jaipur (Rajasthan) did not know that PLHIVs were exempted from replacing blood if used for transfusion which turned out to be a difficult experience for an end user.

**Lack of clarity in government order**

The Rajasthan Department of Consumer Affairs, Food and Public Distribution in April 2010, issued a letter to the effect that all PLHIVs who have a BPL card be directly given AAY cards while those who are not in BPL list be first given a BPL status as per the prescribed norms/procedure and subsequently issued the AAY cards. This government order (GO) did not specify the procedure for identifying a BPL household which turned out to be a huge challenge to secure an AAY card.

> “For all those who do not have a BPL card, the survey has to be initiated from scratch. It will take many years for this. We advocated that since we have the HIV diary, the selection process should be eliminated and we should be considered eligible for the AAY card. But here again the case got stuck at the Nagar Palika level. They were not able to give the serial number which one gets during the BPL survey”.

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**Provisions on paper not translated into reality**

A MGNREGA worker was entitled to unemployment wages if they did not receive work within a fixed period after enrolling for the same. Participants shared that people in Tamil Nadu did not receive their unemployment wages. Another example from Gujarat was that the sarpanch gave job cards but did not give work or salary. If work was not provided, the programme lost its attraction and the job card became just another card without much value.

**Corruption and bribes**

Participants across all states reported payment of bribes to prepare supporting documents (like income certificate, ration cards, etc), get their application forms moving or even to receive the entitlement amount. The bribes mostly related to schemes which offered cash transfers (widow pension, MBPS, old age pension, NFBS, MGNREGA and IAY). The amount of bribe was more for housing schemes which offered huge cash benefits. Overall, corruption and bribes reduced the net transfer of benefits to the users as will be evident in the examples below:

Women reported paying bribes at different levels for getting the **widow pension**. Similarly, for **MBPS** in Orissa, participants reported paying bribes ranging from Rs. 200 to 500 to functionaries at the service delivery points like the revenue inspector, at the block office and to the Sarpanch in order to receive their benefit (refer quote below).
According to a network in Tamil Nadu, corruption issues were very high in the housing schemes. For example, five of the network members were sanctioned patta land number on the paper, but when they went to occupy the same, no land existed. Despite following up with the Collector’s office and writing a complaint letter, the land had not been allotted. According to the network, such incidences were not uncommon. The bribe, as reported in one case was as high as Rs. 20,000 (almost 30 percent of the entitlement), of Rs. 60,000/- received for construction of the house under the scheme. Similarly, paying bribes to the Sarpanch to the tune of Rs. 2,000 – 3,000 to avail the benefits of Mo Kudiya housing scheme in Orissa was also reported.

Corruption at the local level when MGNREGA workers were given ` 80 and sometimes as low as ` 35 and made to sign for ` 100 was a major constraining factor, reported participants from Tamil Nadu and Rajasthan. Under these circumstances, PLHIVs were more likely to discontinue the work.

For the National Family Benefit Scheme, lack of knowledge and cumbersome nature of the application procedures resulted in dependency on middle men who demanded payments upto Rs. 3,000 to get the job done.

In Antyodaya Anna Yojana, women user participants from Gujarat strongly suspected corruption at the FPS when they did not deliver the food grains (refer quote).
Quality and quantity of in-kind transfers, health and education services

The quality of in-kind transfers especially in the food and nutrition schemes (TPDS, AAY, ICDS, MDM) was critiqued by many participants. Some users shared real experiences of receiving inferior quality foodgrains while others had not accessed these schemes based on perceptions or known experiences of other users. The following scheme wise examples illustrate the same:

**TPDS**

Several participants from all states expressed concerns about the quality of food grains available through the TPDS. Many shared that the fair price shops did not offer all the provisions like kerosene, sugar, oil and pulses, citing non-availability as the reason. In case the FPSs offered these provisions, they often did not provide the stipulated quantity. This feedback about leakages or poor quality of food grains is not new to PDS. The new food security bill (pending in the parliament) proposes to address this issue through direct cash transfer programs, food stamps and offering choice of FPSs.

> “In the ration, the rice is for Rs. 1. But, the people are not able to eat that rice because it is very bad and smells terrible. They buy good rice so that they can use it to make idli or appam. They mix the good rice with the bad one and manage. But for cooking purpose very few poor people use it”
>
> – key informant from Tamil Nadu

**AAJ**

Some user participants from Rajasthan expressed satisfaction with the benefit of this scheme. They praised the coupon system wherein they redeemed coupons for rice/ wheat at the ration shop. In Gujarat, however, PLHIVs did not find the wheat flour and rice inedible. They felt compelled to throw away the flour since it was infested with insects. There was no action taken despite complaining about it. This was contradicted by the official from SACS who claimed to have baked *bhakris* (breads) out of the flour and found it to be fine. The Gujarat government had promised strict action in case of complaints.

Users from Gujarat also received varying quantities of the actual entitlement. Ration shop owners claimed lack of availability of grains or sometimes argued that a family of 2 individuals cannot be given the entire quantity. The users in Gujarat thus perceived the AAY scheme to be ineffective and this could discourage others from applying for it.

> “In some aanganwadis, they don’t give anything. They just make children sit together. When the officials come to check and they write down their names and present an inflated figure. The officials should come on surprise visits otherwise aanganwadis get time to prepare for the inspection. If on an average 10 children come, they bring 50 for that day. In my village, I’ve seen with my own eyes that the food was lying open, uncovered, all flies were there. How can HIV positive children, who have low immunity, eat this food?”
>
> – a woman user FGD participant from Rajasthan
ICDS
Participants across all states perceived the food to be unhygienic and of poor quality and hence did not want their children to be consuming such supplements.

MDM
Some participants in Gujarat, Rajasthan and Tamil Nadu expressed doubts about the hygiene levels during the cooking process and opined that receiving raw food grains was better than cooked food. A SACS key informant from Tamil Nadu however felt that the quality of food accessed for MDM was monitored by a nutritionist and hence safe for children living with HIV. NGO key informant from Orissa shared that the MDMS offered insufficient food to children (refer quote).

“The food is not sufficient. First of all the quality of the daal and rice is not good. 2 eggs per week are to be given for one child, but they give only one egg and sometimes do not give eggs at all. They give about 10 or 20 grams of daal and some rice. Almost no vegetables”

— NGO key informant from Orissa

Limitations of health care services
Health risks are a major burden on HIV households’ monthly expenses. Government health care services had constraints which prevent users from accessing them. Crowds and long queues in the district or tertiary hospitals discouraged participants from accessing these services for small ailments, although the MMJRK scheme offered free medical services to all PLHIVs in Rajasthan. A participant shared that due to physical weakness resulting from OIs, they were unable to wait for long hours. Participants also perceived the quality of medicines at the public health care settings to be inferior and often limited to a few general ailments. Medicines for STIs were not available. Some participants believed there was a nexus between the doctors and the pharmacies where free medicines were being misused.

Meagre amount of pension
Several women participants across all the states opined that the widow pension benefit of ₹500 per month was not adequate to meet the needs of a HIV household given the inflation rates and rising costs of essential commodities.

HIV related stigma and discrimination issues
The special provisions in mainstream schemes for PLHIVs led to an inevitable disclosure of the applicant’s HIV status to different levels of officials in the district administration, PRIs and staff at the service delivery points. Many users (PLHIVs) at the grassroots shared that fear (both real and perceived) of disclosure and discrimination was one of the major barriers in the uptake of social protection schemes. They also shared real instances of stigma, discrimination and denial wherein their morality was questioned or in other cases, staff at service delivery points did not believe them to be having HIV since they ‘looked healthy’. The impact of a single episode of discrimination was such that it deterred other users in accessing schemes.
User’s examples of disclosure, stigma and discrimination are enumerated below:

**Disclosure through bus pass/railway travel concession form**
The initial bus pass in Rajasthan had the word ‘person with HIV/AIDS’ written on the card which made the HIV status of the user obvious to the bus conductor. RNP plus and Rajasthan SACS advocated with the state roadways authority for the use of the word ‘immune compromised’ on the bus pass. Users pointed out that although the word immune-compromised was introduced with the intention of camouflaging the HIV status of the user, the new terminology had the bus conductor intrigued about the nature of disease as the person seeking concession appeared to be hale and hearty. The conductor often asked direct questions in public which was embarrassing to the users. They felt constrained in using the bus pass in order to avoid such questions.

Similarly, in the railway concession form, there was disclosure of one’s HIV status to railways staff (ticket checker and ticket issuer) since the user had to identify his/ her eligibility to 50 percent concession for PLHIVs. Both, real and perceived fear of stigma and discrimination at the service delivery points acted as a barrier in coming forward to avail this benefit. A key informant from Gujarat shared that they tackled the discriminatory behaviour of railway staff by filing a complaint following which those officials were asked to give an explanation. She opined that PLHIVs should travel fearlessly and be prepared to fight against discrimination.

Participants from Tamil Nadu shared that they were more comfortable sharing their status as compared to the earlier days of the epidemic because of greater awareness in the general population regarding HIV and AIDS.

**Confidentiality and disclosure issues while accessing MBPS**
In Orissa, a list of all who tested positive at the ICTC was sent to OSACS for processing for the MBP scheme. But there were PLHIVs who did not wish to avail the same for reasons of confidentiality. Their names had to be struck off from this list. This procedure also raised question on the violation of right to confidentiality. Again, in MBPS, HIV widows got the entitlement amount in the form of a cheque through the block office, while non HIV widows got cash from the Panchayat office. These differences were seen as encouraging discrimination and violating confidentiality. Ensuring confidentiality at the village level was a major problem, as evident from the quote here. This prevented some PLHIVs from collecting their cheque from the block office to preserve their confidentiality.

> “Some sweeper informs them that the pension has come. So the whole village comes to know that they have got the pension and they wonder why a healthy and strong and young person is getting it. Then they find out the he is HIV positive. Sometimes the people just tell that he has AIDS and that’s why he is getting a pension. This becomes a confidentiality issue”.

- key informant from NGO in Orissa
Lack of sensitivity to confidentiality issues by the Gram Panchayat

According to the GO of the Rajasthan State government, all HIV households were to be granted AAY cards (refer to the previous subsection on governance issues for details of this GO). Since the Gram Panchayat and Gram Sabha were intimately involved in the identification of BPL and AAY families, PLHIVs had to disclose their status to the Sarpanch to avail the facility. An outreach worker of the network in Rajasthan submitted a list of PLHIVs from his district network to the Gram Sabha for the AAY cards. The Sarpanch disclosed these names to all in the village. This outreach worker faced the ire of his fellow members for this disclosure. Following this incident other district level networks in Rajasthan now got a stamp paper signed from their fellow members (similar to consent letter) while submitting the application forms. But, fear of disclosure continued to prevent many PLHIVs from accessing the scheme.

At the same time, several participants did not mind disclosure of their HIV status so long as it remained restricted to the government official involved with the scheme. They were most concerned about protecting their HIV status from their friends, family and community.

Other forms of disclosure

In Tabibi Sahay of Gujarat, issues with regard to confidentiality and disclosure arose while fulfilling the application formalities (see quote). Similar issues arose when the post man delivered the money order. He often called out loud, “your HIV benefit has arrived”, which was like an announcement on the user’s HIV status to the entire locality. The SACS key informant however opined that a postman was unlikely to know about the HIV status of the recipient but would like to address this matter by notifying the concerned network.

In Palanhar Yojana of Rajasthan, participants had to approach different individuals for the multiple documents. For example, the school principal for the bonafide certificate, the patwari for the income certificate and the sarpanch for letter verifying parents as guardians of the children. This eventually led to disclosure of applicant’s HIV status. Participants feared that these individuals would disclose their status to the community and preferred not to access the scheme.

“Two witnesses are needed from our locality in the mamletdar’s office when he signs the income certificate required for the Tabibi Sahay. When the two witnesses accompany us, we have to explain the purpose of the scheme. If we name any other illness to prevent sharing about HIV, others tell us that we also have ‘xyz’ who is ill, please get his form filled too. They want the same favours for their friends and relatives too. We can’t want to tell them that this is for HIV.”

– men users from Surat, Gujarat
In MGNREGA too, real and perceived stigma prevented PLHIVs from coming forward for registration or securing job cards or receive concession in strenuous labour work. When they did disclose their HIV status, some PLHIVs were given lighter tasks like doing domestic work, some others were told to sit aside without work and in other instances, they were refused work. There was fear of spread of HIV when sharing tasks in an assembly line (refer quote). “PLHIVs should be treated at par with other beneficiaries of NREGA to avoid stigma and discrimination and to enable their empowerment in mainstream society” opined a SACS key informant from Gujarat.

Participants feared stigma and discrimination the most while accessing health care services, be it the ANC related services through the ICDS or the primary, secondary or health care services (refer quote). Discriminatory behaviour by the staff at the BPL counter (in MMIRK scheme of Rajasthan) included asking loudly whether they had come from ‘AIDS’ department, moving away from them, and so on.

With the support of the respective network staff, some users were able to assertively deal with discriminatory experiences at the service delivery points. There were instances of the staff reaching health care settings on a mere phone call from a fellow member to help address discrimination issues.

“There is stigma, because of which they are not able to come forward for registration or job card. People are not allowing them to get into NREGA. They feel that if they share the same basket on the head then they will also get HIV. They feel that if they share a glass of water, then also it will spread. That kind of misconception is still there in rural areas and also self stigma is one of the major barriers for PLHIV. They think that I am a useless person. They don’t work after getting the report saying they are positive.”

– NGO key informant from Orissa

“If one wants the benefit if the scheme, then one has to hide the status. This is the fact. She will be told to keep her child at home or if other parents come to know about it, they may stop sending their children to the aanganwadi. If a pregnant woman discloses her status to the ANM, she will not touch her at all and directly refer her to the CHC. This is what is happening in reality.”

– PPN key informant from Rajasthan

“In Puri there was a lady who tested positive before her delivery. They immediately transferred that lady to Barinda (Private hospital) without administering Nevirapin. She delivered twins. The stigma and discrimination is very high at the health settings. So how can one ensure the Janani Suraksha Yojana? Other women feel discouraged because of this and prefer to deliver in their villages”...

– NGO key informant from Orissa
Many participants suggested that they would prefer to avail schemes through the ART centre or the PPN’s office to avoid disclosure at multiple levels. However, some network leaders opined that the HIV epidemic cannot be ‘faceless’. They preferred to find ways to address stigma and discrimination instead of pressing for confidentiality. An underlying opinion was that when people ‘come out’ in greater numbers about their HIV status, it brings ‘normalcy’ to the epidemic which will contribute in reducing the stigma associated with HIV.

**Gaps in certain livelihood and health insurance schemes**

Livelihood schemes (SGSY and SJSRY) and health insurance schemes are very relevant and useful for PLHIVs. But certain gaps in the programme made them incompatible to the needs of PLHIVs.

**Livelihood scheme**

Except Tamil Nadu, SGSY (a group employment scheme) was not known among all PLHIV users and non users from Gujarat, Orissa and Rajasthan. The key informants too had limited awareness about this scheme. Although, the PPNs in these States were beginning to work on SHGs, but, building a pool of semi-skilled PLHIV workers through SGSY followed by employment generation had not received focus so far.

PLHIVs from different villages in a taluka/ district had to come together to meet the criterion of minimum 20 SHG members. NGOs in Tamil Nadu and Orissa found geographical distance between members as the major constraining factor. Both the states overcame this barrier by having mixed groups of SHGs, that is, PLHIV and non-PLHIV members, but, this required lot of efforts to convince people to come together. Alternatively, networks in Tamil Nadu were mooting for the grant of a special status for PLHIV SHGs, similar to that of SC/STs, so that smaller groups of 5 become eligible for the group loan.

Again, mainstream SHGs had access to NABARD loans and the like, but SHGs exclusively by PLHIVs faced reluctance from banks probably because the latter did not have confidence about recovering the loan amount.

Illness and fatigue were the major reasons for PLHIVs to drop out from the 6 day SGSY training programmes. This could possibly be one of the reasons why SHGs had not met with success pertaining to income generating activities. Hence, training programmes needed to adapt themselves to the special conditions of PLHIVs. Some NGOs opined that positive people’s networks could play a pioneering role in income generating activities because they may have wider access to all PLHIVs across a district and a State as compared to NGOs who may be more localised.

In the case of SJSRY too, except for Tamil Nadu and Orissa, participants from other states did not have knowledge about the benefits of this scheme. This scheme largely remained underutilised as there was only anecdotal evidence of the uptake of SJSRY.
Health insurance schemes
Health insurance schemes like PSI Star health insurance and Kalaignar Kapitu Thittam (KKT) were significant schemes accessed by PLHIVs in Tamil Nadu to cope with the health risks that HIV households were prone to. One of the constraining factors was the lack of uniform knowledge about the eligibility and entitlements about the various health related schemes among the network leaders and members, NGOs and SACS. This needs to be suitably addressed so that users have clarity about their entitlements.

However, gaps due to non-coverage of major illnesses and common ailments like fever and diarrhoea as well as the toxic side effects of the ART, terms and condition regarding forming groups and specific CD-4 count for enrolment made Star health insurance scheme less attractive to users as they ended up spending money for treatment. Though the policy covered children for medical expenses as well as death, the terms and conditions for caretakers to receive the amount were not very clear according to a key informant from SACS in Tamil Nadu.

PLHIVs found the amount of premium Rs. 750 unaffordable. An NGO in Tamil Nadu paid the premium for 15 PLHIVs at the time of registration. But subsequently none of them renewed the policy and lost the money and the benefits. This proves that payment of premium by NGOs or PPNs may not be sustainable in the long run. If the premium amount is reduced, many poor PLHIVs may find it easier to buy the product. Affordable premium amount was suggested to be between Rs. 300-500.

Participants from Rajasthan and Gujarat found relevant alternatives of free health care and therefore did not perceive the need for Star insurance scheme.

Kalaignar Kapitu Thittam (KKT), in Tamil Nadu, was an important health insurance scheme too as it insured the BPL households for hospitalisation and surgeries (costing upto 2.5 lacs). However, weaknesses due to lack of clarity among the card holders about the exact terms and conditions of the scheme, lack of knowledge about the inclusion of PLHIVs in the scheme and experiences related to stigma and discrimination in the hospitals since the KKT card mentioned the users’ HIV status, led to constraints in its use.

Targeting and coverage
Effective targeting and coverage were significant to intensify the intended impact of a social protection programme. This study aimed to capture the relevance of the existing State led poverty alleviation programmes to improve risk coping mechanisms of HIV households. Therefore, the discussion on targeting and coverage is to understand the ability of these programmes to reach HIV households in India.

Targeting BPL households
Centrally sponsored schemes like TPDS, AAY, Annapurna Yojana, SGSY, SJSRY, JAY, NFBS etc. are targeted to BPL households. State specific health insurance schemes like MMJRK (Rajasthan) and KKT (Tamil Nadu) are also targeted to BPL households. As discussed in Chapter one of this study, BPL surveys are held every five years (since 1992) and they have so far been critiqued by scholars for errors in exclusion of poor and inclusion of non-poor.
Conditional BPL status for HIV households

HIV households not in possession of BPL identification were constrained from participating in the aforementioned social protection schemes. However, joint advocacy efforts by the positive people’s networks, SACS and NGOs had resulted in a conditional BPL status for PLHIVs to access a few mainstream schemes relevant to the needs of PLHIVs. For example, a BPL status for inclusion in health schemes like MMJRK (in Rajasthan) and Kalaignar Kapitu Thittam (KKT) in Tamil Nadu and inclusion in AAY for benefit of subsidised foodgrains.

This conditional BPL status was more like a back-door entry into the scheme and did not entitle them to all other social protection schemes meant for BPL households. PPNs were lobbying for a blanket BPL status for all HIV households to enable easier access to several other social protection schemes. In Gujarat, the proposal for inclusion of PLHIVs in the BPL list had been put up before the State AIDS Council (refer to quote). In Orissa too, the chief minister had verbally announced the inclusion of HIV households in the BPL list, but, official notification was yet to come through (NGO key informant from Orissa).

Blanket versus conditional BPL status for HIV households

Several FGD participants argued vehemently in favour of a blanket BPL status for all PLHIVs instead of a conditional one. They opined that a blanket BPL status opens doors to several other social protection schemes, reduces reliance on the time consuming BPL surveys that happen after a long gap of five years and may not necessarily capture their debt ridden poverty. Above all, they considered a blanket BPL status a pre-emptive measure to serve as cushion for children, spouses and parents in case of death of breadwinner and prevent them for reaching a stage of destitution.

However, a few key informants from NGOs and SACS had a different opinion to offer. They felt that a blanket BPL status may brand the PLHIVs as poor and reduce their productivity which was not favourable. They preferred lobbying for special provisions in relevant schemes to avoid the complications of BPL surveys. A key informant from Orissa opined that households that fit into the criteria as specified by the BPL survey should be entitled to the benefits of schemes. Another key informant from Tamil Nadu pointed out that the central and state governments have a fixed quota of BPL households for each state and a blanket inclusion of all PLHIVs in the BPL list is likely to be burden which the government may find difficult to fulfil.

Rural-urban differentials in social protection schemes and implications for participation of HIV households

Housing scheme, IAY is targeted to rural households only. This scheme offers a substantial cash transfer to beneficiaries. Participants of this study, who mainly hailed from semi-urban or

“Now the BPL census for 2010-11 is going to happen. From the 15 districts we have selected 15 villages for the pilot testing. So in this census if the Gujarat government accepts the proposal, then all PLHIVs will be considered under BPL and BPL cards will be issued to them”.

– SACS key informant from Gujarat
urban areas felt a rural-urban differential and wished for low cost housing schemes in urban areas since house rent was a huge burden on the monthly expenses. (Participants residing in Jaipur, Rajasthan shared that the house rent amounted to ` 2,000 per month in the city) Women who had been deserted from their marital and natal homes too expressed the need for a reservation in low cost housing schemes in urban areas.

PLHIVs hailing from semi-urban and urban areas were also unable to access MGNREGA, since it aimed to guarantee employment in rural areas only. Among the PLHIVs residing in rural areas, those incapacitated by poor health found it difficult to cope with manual labour and tended to stay away from it even if they had a job card. This further limited the coverage of this flagship rural employment scheme for PLHIVs.

At the same time, ICDS, a scheme which did not see rural - urban boundaries was perceived to be more common in rural areas by participants from Gujarat and Rajasthan. Additionally, since the ICDS covered children in the age group 0 to 6, PLHIV families with children above the age of 6 could not derive nutritional benefits from this scheme.

Non – participation in MDM
Participants from Gujarat and Rajasthan preferred to send their children to private schools for education because they perceived the government schools to be lacking in quality education. The government schools also did not run classes beyond Grade 7. Therefore, children of such households were not accessing the mid-day meal scheme.

Summary
Procedural issues like restrictive eligibility criteria, cumbersome application procedures, delays in receipt of benefit, opportunity costs; governance related issues like corruption, bribes, leakages, lack of quality in services; HIV related stigma and discrimination resulting from the inevitable disclosure of one’s status along the service delivery line; gaps in certain livelihood and health insurance schemes and targeting and coverage of populations (based on BPL card holders or rural households) have emerged as some of the major constraining factors in the access of social protection schemes by PLHIVs.

Of significance was the plight of APL - HIV households who hailed from the diamond hub of Surat and other business families from Rajasthan and Gujarat. A reduced income along with increased spending on private health care had led to severe constraints on their resources. They were not comfortable in accessing health care or education in government set ups as they perceived their services to be of inferior quality. In such a situation, they were not only not able to use certain schemes (like ICDS, MDM, etc) which are implemented through government schools only, but also found it difficult to continue spending on private health care or education facilities.

The constraints related to cumbersome and costly application procedures, quality/ quantity of the food grains, corruption and leakage at the service delivery points are not new and have been reiterated in other research studies on evaluation and performance of social protection schemes in India. (Refer to Chapter 1 for details) The latest National Food Security Bill (pending in the parliament of India) and the UID-Aadhar have been envisaged in the eleventh plan to overcome some of these constraints, but it will be too early to predict the outcomes of these projects.
This section is woven around two of the themes explored in the study, that is, gender differentials in the access of social protection schemes by PLHIVs and perspectives on mainstream social protection schemes versus target schemes for PLHIVs.

**Gender aspects in accessing social protection schemes**

**Gender inequalities vis-à-vis need for social protection schemes**
Research conducted over the past decade has revealed that gender roles and relations directly and indirectly influence the level of an individual's risk and vulnerability to HIV infection.\(^1\) Care givers in the HIV households are generally women and many among them are also infected. The additional responsibility they assume results in poor health seeking behaviour. Women face greater stigma and there is lower awareness among women about where to go for voluntary testing in comparison to men. More women living with HIV are asked to leave home after testing positive than men. Widows are denied right to property and face stigma on three counts— as women, PLHIV and widows. Many HIV positive women live alone and are economically worse off than other HIV households.\(^2\)

Given this situation, existing gender inequalities and norms are likely to influence the access to information and services, related to social protection schemes. Therefore, this study included questions related to gender differentials in access to social protection schemes, utilisation, and preferences in accessing the schemes. The study also explored the extent and type of stigma and discrimination faced, attitude of the service providers and challenges faced by both men and women.

**Social protection schemes relevant to men, women or children**
The above table shows gender wise eligibility criteria of different social protection schemes explored in this study. Schemes like widow pension, NFBS and JSY have a gender based eligibility criteria, that is, they are targeted to women only. Widow pension and NFBS stem from the fact that women, traditionally not part of the workforce, are rendered vulnerable and pushed towards poverty when they lose their spouse and therefore need to be assisted by the State to have a recurring income. However, Orissa is an exception here because the Madhu Babu Pension Scheme targets all PLHIVs, irrespective of gender. JSY, a scheme under NRHM is aimed to increase institutional deliveries of women from BPL/ APL households and hence the gender specific criteria.

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\(^1\) Integrating Gender into HIV/AIDS Programmes, A review paper, Department of Gender and Women's Health Family and Community Health. World Health Organisation, 2003

Table 5: Social protection schemes relevant to men, women and children

<table>
<thead>
<tr>
<th>Type of Scheme</th>
<th>Orissa</th>
<th>Gujarat</th>
<th>Rajasthan</th>
<th>Tamil Nadu</th>
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<td>Chldn</td>
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</table>

NA: Not applicable; Chldn: Children
Other schemes related to food and nutrition, livelihood, health and housing are not necessarily gender specific. For example, food and nutrition schemes like PDS and AAY are targeted to BPL households. MDM and ICDS have an overall objective to improve the nutritional status of children in the country. Housing and livelihood schemes like NREGA, SGSY and SJSRY too do not discriminate between men and women, though it is likely that women may receive preference in certain cases to encourage them in their endeavours. Schemes like Palak Mata Pita (of Gujarat), Palanhar (of Rajasthan) and OVC Trust (of Tamil Nadu) provide assistance to children affected by AIDS and the guardians of these children often receive the benefits.

Participants’ perspective on gender bias
As discussed above, eligibility criteria of most of the schemes are not gender specific (except for widow pension, NFBS and JSY), but, there was a difference of opinion among several men and women participants of how the schemes were organised more in favour of women than men, some of whom were also in dire need of social protection schemes. This was particularly evident in Tamil Nadu where more women were using and benefitting from social protection schemes. For example, in livelihood schemes providing loans to individuals, women received preference as compared to men who could not provide property as security, a condition which did not apply to women. Thus, men’s requests were turned down. However, men generally came forward in applying for the land pattas under the housing schemes, especially those who had been abandoned by their families after knowing their HIV status.

“I think that women are given preference in the social protection schemes in Tamil Nadu rather than men. Men are not being considered, of course if they are much affected and below poverty line, then they are considered but women are given preference in all the schemes”

– key informant from SACS in Tamil Nadu

Women opined that men were not as vulnerable in a patriarchal society and very few would face a situation similar to that of widows. Some polarised opinions included that men should not be included in social protection schemes since they were primarily responsible for infecting their wives. Few women and men participants from Rajasthan opined that there should be a scheme similar to widow pension, which aids men who are destitute or have to single handedly rear their children especially when the disease has progressed to the advanced stage.

“If a man’s wife dies, the man too faces a lot of difficulties. Even if they are physically okay, they are not able to get jobs. If any employer gets to know of their condition, they do not employ them. So even if they want to do any work, they cannot. His social condition becomes such that he is helpless. He is as needy and destitute as the women.”

– a male from non-users FGD in Rajasthan
However, in the absence of gender disaggregated data regarding the uptake of schemes, it is difficult to conclude whether men or women are utilising or benefitting more than the other. Participants perceived certain gender related factors to be facilitating or constraining for both men and women. These are described below:

**Gender related facilitating and constraining factors**

**Access to information about the schemes and procedures to apply**
Women, in general, had lesser information as compared to men about the schemes, type of supporting documents required and who to approach for the same. This was also related to their inability to attend network meetings due to lack of family support. Low literacy levels among women too posed a barrier in access to information about the services. Women often paid money (which were sometimes huge amounts) to ‘agents’ or middlemen to fill up the application form and submit the same or to get the necessary certificates. There was possibility of getting duped also by such agents who took advantage of the naiveté of the women applicants.

However, women participants from Tamil Nadu and Rajasthan pointed out that they felt better equipped with information about the schemes and their application procedures with the help of their network. The group approach adopted by the women’s groups facilitated processes for women.

**Mobility and access**
Access was also related to mobility. Women especially from rural areas could not access district/block headquarters on their own. Moving out of the house cast suspicions about their character, especially the widows (refer quote). Restricted mobility also affected women’s membership and their participation in network meetings. In contrast, men were more mobile at any time of the day. They were out of the house for work or even to attend network or other meetings.

> “When we go out from home for availing the schemes we are blamed by our family and neighbours talk about our character. They don’t understand that we have to travel from one office to the other”
> — women users in Orissa

**Lack of self confidence**
Some participants felt that lack of information and restricted mobility led to low self confidence in women due to which they hesitated to speak to government officials. Men, on the other hand found it easier to speak with officials and present their case to them. Women felt the need for a male relative of a DLN/SLN staff member to accompany them while approaching different government officials involved in the delivery of a scheme.

**Support from Family/in-laws**
In Tamil Nadu, families preferred women to go out and avail the schemes because they perceived them to have a better sense of saving as compared to men who tended to blow up the money on ‘unnecessary’ items like tea/tobacco/cigarette. Another reason for this
preference was that households perceived women to get more sympathy because of their gender which supposedly expedited the work. Participants from Orissa shared that family members did not allow women to access schemes for fear of losing family honour (refer quote). Participants from Rajasthan shared that ‘male preference’ was prevalent across the board for all aspects related to health care, nutrition and social protection schemes. In Gujarat, participants did not report any discrimination between men and women at the family level regarding uptake of social protection schemes.

Some women found it difficult to procure the death certificate of the deceased husband or other relevant documents like the ration card, when they were estranged from their in-laws. A participant from Rajasthan shared that she was compelled to write the address of her in-laws house for widow pension because of the ration card. Since she did not stay with them, the verification officer rejected the form. She had to take a lot of effort to make a new independent ration card and consequently apply afresh for widow pension.

**Difference in perception of significance of social protection schemes**

Some participants perceived women to be more sincere towards seeking benefits from social protection schemes. They opined that women valued the small amounts received as pension or otherwise and hence were willing to diligently pursue their applications as compared to men who did not perceive the amount of entitlements to be huge enough to forgo daily wages and follow up the application process.

**Attitude of the service providers**

Some men participants perceived that women received sympathy from service providers because they were seen as ‘poor victims’ whereas men were believed to cause the spread of HIV due to their promiscuous behaviour. However, women shared that the male service providers gave questioning looks about their morality/sexuality on learning their HIV status. A few widows shared experiences of overtures made by male service providers which deterred them from following up with their application forms. A participant (a female sex worker) shared that she was humiliated by an official from the social welfare department when he learnt that she was a ‘dhandewali’ (a woman engaged in sex work).

Overall, what came across was that if the implementing staff at the service delivery points were sensitised to this issue, they gave preference to women. In Tamil Nadu, procedures for availing the schemes were delayed in case of men whereas preference was given to women.
Gender differentials in stigma and discrimination
There was fear (real and perceived) of stigma and discrimination due to disclosure of HIV status which prevented both men and women from accessing schemes. However, there were gender variations in fear of disclosure and experiences of stigma and discrimination as reported by participants across all states. Unpublished data of OSACS seems to suggest that fewer women than men in Orissa were accessing MBPS due to the fear of stigma and discrimination.

However, men seemed more concerned than women about disclosure of their HIV status which prevented them to collect the money of MBPS from the block office. Women did not hesitate as much since they were more concerned about the benefit to the family. An NGO adjusted its STI clinic timings to suit the men who did not want to face exposure and thus preferred to partake of the services late at night. Women however attended the clinic in the morning.

Women in Tamil Nadu who belonged to SHGs and wore uniforms were not intimidated by fear of disclosure as they worked and moved in groups. In Rajasthan, it was challenging to have women involved in the district level networks because they feared stigma and discrimination.

Membership of the network
According to a participant, women members were outnumbering the men in membership of positive people’s networks and access of social protection schemes in Tamil Nadu. A possible reason cited for this was that more men were dying of AIDS as compared to women which gave rise to a significant widow population who were accessing schemes applicable to them.

Preference of specific schemes
Although there was no data to support the same, participants perceived that scheme NREGA was not so popular among women in Orissa due to the manual work involved in the scheme. In contrast, in Tamil Nadu more women were utilising NREGA. Where schemes were simple in their procedures and there was support of the network, more men were ready to pursue them, as in the case of Tabibi Sahay and Jatan Project in Gujarat. More men were registered for ART and thus could avail of the schemes associated with the ART centre, such as the bus pass facility.

Schemes for women in vulnerable situations and MSMs and TGs
Orissa was the only state where single women, female sex workers, MSMs and TGs could avail of a cash transfer scheme like MBPS due to a blanket inclusion of all PLHIVs in the same. However, there seemed to be limited uptake of this scheme because these persons did not want to disclose their identity. There was anecdotal evidence of uptake of NREGA by TGs in rural Gujarat (Chuwal district). Participants from Gujarat mentioned that MSMs and sex workers faced double stigma, one related to HIV and the other due to their sexual behaviours.
Transgenders (hijras), for several reasons found themselves unable to access several social protection schemes. Widow pension, one of the popular schemes was inapplicable to transgenders. Since the transgenders leave their family name to adopt a different identity, they could not produce documents like ration card and voter’s identity card which were significant for availing food and nutrition schemes.

**Lack of gender disaggregated data**
Maintaining gender disaggregated data was not a part of the monitoring system of most of the schemes. There was evidence of gender disaggregated data for the utilisation of MBP scheme in Orissa and the Jatan project in Gujarat only.

**Summary**
Gender roles like reproductive roles of women and different norms for men and women’s marriage, sexual behavior affect the gender needs of men and women, which also determines social protection schemes they need. The social protection strategies need to address the practical gender needs of men and women among the PLHIVs. In Tamil Nadu, positive discrimination in the favour of women is evident in the implementation of the social protection schemes where special consideration is given to women in terms of selection criteria and preference.

Perceived barriers for men to access schemes need careful consideration and a change in attitude (for example, too small amount, no time, not enough, no need and so on). There is a need to simplify procedures that discourage women and men to take full advantage as well as enhance the amount of funds being distributed under each scheme so as to enable sustenance. Gender disaggregated data needs to be maintained for the utilisation of all the social protection schemes. Gender mainstreaming needs to be introduced into the training of PPNs and NGOs to make them more gender sensitive and supportive in the utilisation of social protection schemes.

**Mainstream social protection schemes versus target schemes for PLHIVs**
Leveraging benefits through mainstream social protection schemes has presented several advantages that facilitated their uptake by PLHIVs. However, there are inherent disadvantages too that constrained their uptake thereby creating a demand for target schemes for PLHIVs. This subsection discusses the divergent opinions of participants on mainstream social protection schemes versus target schemes to meet the social protection needs of PLHIVs.

**Preferences and concerns regarding mainstream schemes**
Those who preferred convergence gave the following reasons:
- Mainstreaming meant an inclusive approach
- Mainstreaming relied on existing resources and hastened implementation
- Mainstreaming leads to reduced stigma
- Mainstreaming meant benefiting other vulnerable groups

These are elaborated below.

**Mainstreaming – an inclusive approach**
Mainstreaming meant an inclusive approach and not isolating the PLHIVs through disclosing their HIV status to the general public. This was clearly articulated by participants from Orissa and Gujarat.
Mainstreaming relied on existing resources
Several of the participants from all the four states emphasised that tapping mainstream schemes rather than creating new ones helped to maximise the existing machinery to execute the scheme and reach benefits to PLHIVs. This saves time by providing immediate access to the benefits, leads to system strengthening and also reduces stigma.

An interesting observation by key informants from Tamil Nadu, Rajasthan and Orissa was that inclusion of PLHIVs in existing schemes would not deprive others as the uptake of these schemes was generally low. Those from Orissa were emphatic that poor PLHIV households should get preference in mainstream schemes because they were more likely to be pushed into destitution due to their positive status.

Mainstreaming leads to reduced stigma
Several participants opined that as greater numbers of PLHIVs come forward to avail the schemes, the more it leads to acceptance, thereby having a positive impact in addressing stigma and discrimination in HIV/AIDS. The schemes should be made more ‘lucrative and attractive’ so that people can lead a better life, opined a participant from Rajasthan.

Mainstreaming helped other vulnerable groups
Other vulnerable groups came forward to access the Madhu Babu Pension scheme which was extended to all PLHIVs in Orissa due to the extensive media coverage about the scheme. The current lobby by NGOs to increase the amount of pension from the current ` 200 to ` 500 would benefit these groups as well.

Some participants expressed concerns about the challenges associated with accessing mainstream schemes. They referred to the procedural issues and cumbersome application processes, disclosure of HIV status leading to stigma and discrimination and the quality of services (especially the food grains received in nutritional schemes like PDS and AAY). (These were also the constraints faced by users as discussed in Section 3.b on constraining factors)

SACS key informants from Tamil Nadu and Rajasthan shared that mainstreaming often required them to prepare proposals on the special provisions/ entitlements being sought for along with an estimate of the burden it will cause to the department. If the key officials got transferred, the mainstreaming departments had to redo the ground work with the new officer. This required constant follow up till the efforts attained fruition.

One of the other limitations of accessing mainstream schemes was when the PPNs and SACS had to discriminate between PLHIVs leading to a partial access of a scheme. For example, the Department of Social Justice and Empowerment (SJ&E) in Gujarat initially announced the Tabibi Sahay for all PLHIVs in the State. Having received almost 1.5 lacs applications, the Department of SJ&E felt they may not have sufficient funds for all PLHIVs in the list. Instead of losing the opportunity altogether, GSNP+ asked to prioritise PLHIVs on ART over non-ART ones. This has led to a feeling of discontentment among PLHIVs who had been left out of the scheme.

Target Schemes for PLHIVs
Target schemes refer to schemes exclusively for PLHIVs to address their specific needs. For example, provision of free ART drugs at select sites in all States through NACO. PPNs and
NGOs arranged for nutritional supplements, opportunities for livelihood, financial support for children’s education for PLHIVs, but, often through private donations.

Target schemes or special schemes for PLHIVs found favour among several participants from all four states. The reasons for this preference are explained below:

- Restricted disclosure of HIV status
- Easy Access
- Improved reach out
- Addressed specific needs

**Restricted disclosure of HIV status**
Preference for target schemes stemmed from the unpleasant stigma and discrimination experiences caused by disclosure of HIV status, while accessing mainstream schemes. Participants were comfortable with disclosure in the ART centre or the network office because here they met people with a shared experience of living with HIV. Accessing target schemes also led to implicit disclosure of HIV status. But participants opined that it is easier to sensitise few persons at the service delivery site in comparison to people at large, as is the case with mainstream schemes.

**Easy access**
Another reason for preference of target schemes was the long drawn application process along with opportunity costs of the mainstream schemes and periods of delay. A participant opined that PLHIVs had to grapple with illness and disease and depleted financial resources. In such circumstances costs of application for social protection schemes and delay in receiving the benefit added to the pain of difficult times being faced by PLHIVs. Participants suggested the need for instant relief and gratification through target schemes for PLHIVs. Comparisons were drawn with the ease and convenience of accessing ART treatment at the ART centres in their block, district or State.

**Improved reach out**
A NGO key informant from Orissa opined that more PLHIVs would be able to access target schemes thereby increasing the reach out. Also, in mainstream schemes, PLHIVs competed for resources meant for a larger group of vulnerable people, but, in target schemes, the resources were diverted exclusively for PLHIVs.

**Addressed specific needs**
A participant suggested that while the society’s attitude towards HIV positive persons is in transition and a stigma and discrimination free society may need more years of advocacy work, making a couple of target schemes along with mainstream schemes would strike a balance in addressing the specific needs of PLHIVs. Another reason to support this suggestion is that some needs are very specific to PLHIVs and mainstream schemes may not fit the bill. For example, care homes for AIDS orphans (running in Gujarat and Rajasthan).

A participant from Gujarat stated that there should be specific schemes for children of PLHIVs, for their higher education, in the form of quotas or reservation or fee waivers. She opined that it may not be possible for the government to provide this type of benefit to all households and hence target schemes would be a better approach here. Several participants expressed the need for devising livelihood options keeping in mind their health limitations.
Participants in favor of mainstream schemes pointed out concerns like stigma and discrimination and the issue of sustainability in devising target schemes. Stigma and discrimination, being a complex issue, pervaded both mainstream and target schemes. A section of participants opined that target schemes implicitly disclosed one’s HIV status by virtue of the PLHIV coming forward to receive the benefit. This is likely to lead to labelling and isolation of PLHIVs during the process of accessing such target schemes. Few participants were concerned about the sustainability of target schemes when funds would eventually dry up.

Summary
The table below summarises the participants’ divergent views on preference for mainstream schemes versus target schemes.

Table 6: Participants’ perspectives on mainstream schemes versus target schemes

<table>
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<tr>
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<th>Advantages</th>
<th>Concerns</th>
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<tr>
<td><strong>Mainstream Schemes</strong></td>
<td>• An inclusive approach</td>
<td>• Disclosure of HIV status</td>
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<tr>
<td></td>
<td>• Taps existing resources</td>
<td>• Complicated application processes</td>
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<td></td>
<td>• Leads to reduced stigma</td>
<td>• Rigid eligibility criteria</td>
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<td></td>
<td>• Helps other vulnerable groups</td>
<td>• Difficulty of data</td>
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<td></td>
<td></td>
<td>• Constant advocacy efforts needed</td>
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<td></td>
<td></td>
<td>• Quality of services</td>
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<tr>
<td><strong>Target Schemes</strong></td>
<td>• Limited disclosure</td>
<td>• Stigma and discrimination</td>
</tr>
<tr>
<td></td>
<td>• Easy access</td>
<td>• Unsustainable</td>
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<tr>
<td></td>
<td>• Greater reach out</td>
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<td></td>
<td>• Addresses specific needs</td>
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Leveraging benefits through mainstream schemes is a relatively recent experience in India. Many participants saw the advantage in using mainstream schemes as it taps existing resources and falls in line with the strategy of convergence outlined in NACP – III. However, complicated and costly application processes along with confidentiality and disclosure issues had constrained participants from accessing them.

On the other hand, participants preferred target schemes as they were easier to access. While there are advantages in the form of easier application processes and lesser delays in receipt of benefits, there are inherent disadvantages of stigma or eventual drying-up of funds.

If mainstream schemes have to be made more popular, then mainstreaming initiatives need to harness the facilitating factors and aim to eliminate or address the constraints.
Successful strategies in promoting the uptake of social protection schemes by PLHIVs

Utilisation of mainstream social protection schemes PLHIVs is a recent phenomenon. Therefore the strategies discussed are not a statistical reflection of the numbers of PLHIVs who benefitted or the amount of entitlements received. The success is more about the add-on or new strategies or changes in certain aspects of the mainstreaming initiatives to fulfil the social protection needs of PLHIVs. This section also presents a few case studies to highlight some flagship schemes or strategies across the four states.

Successful strategies that promoted the uptake of social protection schemes among PLHIVs include the following:

- Special provisions for PLHIVs within mainstream social protection schemes
- Routing of schemes through the ICTC/ ART/ link ART centre
- Routing of schemes through the legal aid clinic (in the case of Tamil Nadu)
- Empowerment of positive people’s networks to deliver social protection schemes

Special provisions for PLHIVs within mainstream social protection schemes

Participation in mainstream social protection schemes has been a reality for PLHIVs in India due to the special provisions, in the absence of which positive people often found themselves excluded from the coverage of such schemes. These special provisions came in the form of:

- Relaxation in eligibility criteria.
- Inclusion of PLHIVs as vulnerable groups in schemes meant for such groups.
- Conditional BPL status for schemes related to priority needs of PLHIVs.
- Provision of additional benefits along with the regular benefits within the same scheme (for example, provision of double nutrition through ICDS for malnourished children)

Relaxation in eligibility criteria

As discussed in Section 3.b of this study, restrictive eligibility criteria were a major constraint in accessing several social protection schemes. However, relaxation in the restrictive criteria helped to gain entry into the scheme. The illustrations are presented below:

Widow pension: In Rajasthan, the minimum age criterion of 40 years was relaxed to 18 for HIV widows. Also, widows were rendered ineligible to widow pension or the same was discontinued if she had a son above the age of 25 years. This criterion was also laid to rest in the case of HIV widows wherein she was entitled to a lifelong pension. However, remarriage of widows was encouraged through an incentive, that is, a one-time grant of Rs. 15,000 in which case the widow pension ceased to continue.
Palanhar Yojana in Rajasthan aims to provide care to destitute children through close relatives who are called their Palanhar (guardian). This is a conditional cash transfer scheme in which money is granted to the eligible applicant for the education (for school fees, books and uniform) of children upon submission of a bonafide certificate from school. This scheme is applicable to only the youngest child of a regular applicant and is valid till the child turns 15 years old. However, in April 2010, this scheme was extended to all children of a HIV household, irrespective of the HIV status of the child.

Inclusion of PLHIVs as vulnerable groups in schemes meant for vulnerable groups

Some states had schemes and provisions for vulnerable groups such as persons with disability, elderly, children and persons living with chronic health conditions such as cancer, TB and leprosy. Positive people’s networks and the SACS tapped such schemes for PLHIVs to accrue similar benefits. The examples are given below:

**Bus travel concession:** persons with chronic health conditions namely, disability, cancer and TB were entitled to a 75 percent concession in bus travel to health care set ups in Rajasthan. Inclusion of HIV in the list of chronic illness (*asaadhyaa rog*) helped PLHIVs to receive a similar concession while travelling to the ART centre. (Refer to case study 1: **Bus travel concession to ART centre in Rajasthan**, for more details)

**Case Study 1: Bus travel concession to ART centre in Rajasthan**

Inclusion of HIV as chronic condition: Bus travel concession through the State Roadways Transport was available in Rajasthan only. (The first GO in this regard came in 2003). Rajasthan State AIDS Control Society (RSACS) and Rajasthan network of positive persons (RNP+) successfully advocated with the Rajasthan State Roadways Travel Corporation (RSRTC) for a 75 percent bus travel concession pass for to and fro travel from residence to the ART centre. The fact that a similar concession was being offered by RSRTC to persons with cancer and disability helped secure one for PLHIVs too, by

“I get Rs. 500 from widow pension and Rs. 675 from Palanhar Yojana. This is my only source of income right now. I was asked to leave my husband’s house after his death. I am trying to fight a legal case with my inlaws for the rights of my child. The doctor tells me to have pomegranate juice and milk on a regular basis. But it is not possible given the inflation.”

– a woman user FGD participant from Rajasthan

“This month, under the Palanhar Yojana, my two children have availed Rs. 2000 each for school uniforms and books. I am also getting Rs. 675 per child per month which is helping me to bear the school expenses”

– a male user FGD participant from Rajasthan
considering HIV as “asaadhya rog”, which means serious or chronic illness.

**How to apply:** The application form for this concession was available at the ART centre. Supporting documents like HIV status report, ART diary along with a photograph, address proof needed to be attached to the application form. A panel of three doctors verified the HIV report and photograph of the applicant. Following this, the residential address was verified by the district level network (DLN) office and the final set of documents were submitted to the relevant bus depot manager who assigned a PID number to the user and signed/stamped the bus pass. This pass however, needed to be renewed periodically.

**Advantage of scheme:** Users found the bus travel concession very useful and advantageous as they had to bear only 25 percent of the travel expenses. They shared that the 75 percent they saved could be diverted to nutrition related expenditures which were a high priority area.

**Field level experiences:** A procedural difficulty was encountered in the implementation of the scheme, as in, RSRTC insisted on a list of all PLHIVs from RSACS (since it was a competent authority) to issue the respective bus pass for all PLHIVs, so that genuine HIV positive people get the benefit. RSACS was unable to provide such a list for two reasons, first that as per the directives of the Supreme Court, a PLHIVs status must be kept confidential and second that such lists are being maintained only by the ART centres. This difficulty was overcome by having a panel of 3 doctors to certify that the applicant is indeed HIV positive and in need of ART treatment.

**Disclosure and discrimination:** The HIV status of the bus pass user was evident to the bus conductor since the word ‘person living with HIV’ was mentioned on it. Many reported stigma and discrimination by bus conductors or others at the service delivery points. Some PLHIVs courageously handled the discriminatory behaviours which set an example for other PLHIVs who felt that they should be assertive and demand what is rightfully theirs. Subsequently in 2010, RNP plus and RSACS advocated with RSRTC to have the word ‘immune compromised’ used in bus pass card instead of the hitherto ‘person with HIV/AIDS’. Users pointed out that although the word immune-compromised was introduced with the intention of camouflaging the HIV status of the user, the bus conductor’s lack of knowledge about the same had them asking what is the disease and why are they asking for a concession when they appear to be seemingly hale and hearty. This was embarrassing to the users who felt constrained in using the bus pass in order to avoid such questions.

**Suggestion:** Users suggested the expansion of concession for travel related to OIs treatment as well. Participants justified this suggestion because 25 percent of the travel cost was borne by the user leaving little scope for misuse of the bus pass.
Tabibi Sahay was a mainstream scheme of the Gujarat Department of Social Justice and Empowerment which provided a cash assistance of `500 per month to buy nutritious food and medicines to persons having TB, leprosy or cancer. In October 2009, following advocacy by networks of people living with HIV and Gujarat SACS, socially and economically backward PLHIVs on ART were also included in this scheme.

A ‘disable pension’ in the name of Madhu Babu Pension Scheme was available in Orissa to the elderly, disabled and widows. This scheme was extended to include all PLHIVs in the state irrespective of age, caste and gender (Refer to case study 2 on Madhu Babu Pension Scheme in Orissa for more details).

**Case Study 2: Madhu Babu Pension Scheme of Orissa**

**Inclusion of PLHIV as vulnerable group:** The Madhu Babu Pension scheme (MBPS) is the most popular scheme availed by the PLHIVs in Orissa. It was earlier described as a ‘disable pension’ which covered the elderly, widows and persons with disability. The sustained advocacy efforts of the networks of people living with HIV, UNDP and the SACS resulted in the inclusion of PLHIVs in this pension scheme in 2008. A yearlong advocacy through a series of events and engagement with the state government, civil society organisations, media, legislature, helped in building public opinion to include PLHIVs in MBPS. Use of suitable spots on radio and television with PLHIVs helped in reaching the information to all, even the remote areas and villages.

**How to apply?** The documents needed for applying for the scheme included proof of HIV status, address proof, bank account number, voter ID card of women applicants, deceased spouse’s death certificate and his voter ID card. The ICTCs had the requisite form which was duly filled by the applicants and sent to OSACS who further forwarded the same to the Department of Women and Child Development. Following an approval, the money was transferred to the bank accounts of PLHIVs through the district administration.

**Advantages/ Benefits of the scheme:** All PLHIVs irrespective of age, marital status, sex, economic status were eligible to apply for the scheme. Though the benefit was a meagre `200, it was much valued by PLHIVs because this was the first time that the Orissa government had considered extending benefits to all the PLHIVs. The pension card served as an identity, ensured linkages with a bank, self help group and the community. One of the NGOs in Orissa facilitated the process of availing the scheme to PLHIVs through their link workers (outreach workers in rural areas) thereby maximising the scope of this project. This scheme became popular among eligible people in the general population after PLHIVs were included in it.

**Response to challenge of incorrect addresses and names:** Sometimes, PLHIVs were unable to give correct names or addresses at the ICTC or did not notify any changes in their addresses/names. In such cases, the entitlement cheque bounced back. ICTC counsellors tried to trace the addresses through their outreach work, but it was not easy. Efforts were being made to build linkages with the link worker project and the ICTC to motivate the HIV positive people in the village to apply for the scheme as well as verify
their addresses for follow-up. Currently, in case of an incorrect address, the applicant was informed through the network of people living with HIV to take the voter ID card and collect the pension from the township office and intimate the correct address. To deal with the issue of confidentiality the verification was done by the ICTC officer or ICTC supervisor.

**Response to the challenge of lack of bank account:** There was a demand from the NGOs and networks to have a uniform mode of cash transfer, through the bank account of the user. But this was a problem, especially in villages where PLHIVs did not have a bank account. As an alternative, if a PLHIV took the entitlement cheque to the Commissioner and told him that he/she could not afford to open a bank account, he gave a self check in return for their crossed cheque.

**Challenge related to confidentiality and disclosure:** The list of all who tested positive at the ICTC was sent to OSACS for processing for MBP scheme. But there were PLHIVs who did not wish to avail the same for reasons of confidentiality. Their names had to be struck off from this list. This procedure also raised question on the violation of right to confidentiality. HIV Widows got the entitlement amount in the form of a cheque through the block office, while non HIV widows got cash from the Panchayat office. These differences were seen as encouraging discrimination and violating confidentiality. This prevented some PLHIVs from collecting their cheque from the block office to maintain confidentiality. This challenge however needs to be suitable addressed.

Cases of AIDS orphans being dumped by their guardians in the Care Home in Gujarat due to financial difficulties prompted GSNP+ to tap the **Palak Mata Pita Yojana** in which orphaned or destitute children’s guardians receive a cash assistance of ` 1000 per month to meet the educational and nutritional needs of the child. Inclusion of HIV household children in the Palak Mata Pita scheme was a recent outcome of the advocacy efforts of GSNP+.

**Conditional BPL status for schemes related to priority needs of PLHIVs**

As discussed in Section 3.c, several social protection schemes are targeted to BPL households, and PLHIVs not in possession of BPL status identification card found themselves uncovered in the poverty alleviation programmes. Successful advocacy on part of different stakeholders helped PLHIVs with a conditional BPL status for the purpose of the specific scheme in question. These schemes addressed the priority needs of PLHIVs, that is health and nutritional needs. The following examples illustrate these:

**Antyodaya Anna Yojana:** Based on the GoI notification in this regard, Rajasthan’s Department of Consumer Affairs, Food and Public Distribution in April 2010, issued a letter to the effect that all PLHIVs who have a BPL card be directly given AAY cards while those who are not in BPL list be first given a BPL status as per the prescribed norms/ procedure and subsequently issued the AAY cards. Since the above notification, the networks in Rajasthan were proactively approaching the district food and supplies department with applications of their respective DLN members for issue of AAY cards. Few PLHIVs, who had got the AAY cards, were beginning to get the benefits while many others were waiting for their applications to be processed.
**Mukhya Mantri Jeevan Raksha Kosh Yojana** (MMJRK) was an insurance scheme initiated in Rajasthan in January 2009, for the BPL families, by the Department of Medical, Health and Family Welfare, to provide free secondary and tertiary health services through the government health system. MMJRK was extended to include PLHIVs in December, 2009 by according a BPL status to PLHIVs for the purpose of this scheme only. PLHIVs in Rajasthan had begun to apply for the BPL health card to avail of free medical facilities.

**Kalaignar Kapitu Thittam (KKT):** Tamil Nadu state government and STAR Health and Allied Insurance Company Limited collaborated to initiate a scheme called KKT in June 2009, to provide cashless transaction insurance for a host of identified high-cost medical contingencies needing surgical care and hospitalisation (in empanelled hospitals) to the insured BPL population (with annual less than Rs. 72,000 per annum). HIV households were included in this scheme to meet with their health related needs.

The Surat city of Gujarat had seen many affluent PLHIVs who initially took ART treatment from private health facilities, but were now unable to bear the costly second line ART treatment. A BPL status enabled them to seek free second line ART treatment from select ART centres in the state. Many PLHIVs, with support and guidance of the State Level Network in Gujarat were approaching the district administration for BPL cards only for the purpose of second line ART treatment.

Many PLHIV have been able to successfully access second line ART through advocating with the district administration to acquire BPL cards, support for this came through the Gujarat Network for Positive People

The government orders specifying the special provisions for PLHIVs, as discussed above, are testimonies to the successful mainstreaming initiatives in the different states. These special provisions have significantly helped PLHIVs to participate in social protection programmes and receive benefits that have positively impacted their risk coping mechanisms.

**Routing of schemes through the ICTC/ART/link centre**

The application forms for schemes like the widow pension, MBPS, Palanhar, Tabibi Sahay, travel concession (bus and railway travel and the Jatan project) were available in the ICTC/ART centre. A district level network member usually provided guidance in filling the form and explained the list of the supporting documents required to the prospective applicants. The ICTC/ART centre formed the base for initiating the process following which the duly filled forms were usually taken to the respective department office (bus depot, social welfare department, etc) for approval. The disbursal channel depended on the provisions of the scheme (for example, bank transfer, money order or cheque or cash in case of travel assistance). The ICTC/ART centres offered a comfortable environment to PLHIVs as they did not fear disclosure or discrimination.

**Routing of schemes through the legal aid clinic in Tamil Nadu**

The legal aid clinic, housed in the ICTCs of 16 districts in Tamil Nadu play an instrumental role in guiding PLHIVs to apply for schemes and providing help in preparing crucial documents like the ration card or affidavits to be attached as supporting documents with the application. *(Refer to Case Study 3: Legal aid clinics in Tamil Nadu for more details)*
Case Study 3: Assistance in applying for social protection schemes through the legal aid clinics in Tamil Nadu

Mainstreaming initiative: Tamil Nadu State AIDS Control Society (TANSACS) partnered with the State Legal Services Authority and UNDP to set up Legal Aid Clinics (LAC) for PLHIVs to access free legal services in the districts, work towards preventing stigma and discrimination and ensure livelihood rights and opportunities for PLHIVs. The LACs functioned within the coordinated service delivery mechanism of the Legal Services Authority, TANSACS, district-level network and the district administration.

Role of LACs: Legal Aid Clinics were functioning in 5 districts since 2009. Subsequently, from February 2010, 11 more LACs were activated, totalling to 16 such clinics in the state. LACs are housed in the district ART centres which ensured easy access to PLHIVs. A full time social worker and an advocate from the district legal service authority are available for 3 hours for two to three times a week. The advocate focuses on legal issues and the social worker assists in the non-legal work for example, in submitting applications for availing social protection schemes or application for land pattas in Indira Avas Yojna (IAY). The LACs created awareness about legal rights among PLHIVs because of which they gained confidence to avail services of the legal cell whenever they had legal issues. Generally, women accessed the legal services for cases related to property disputes. Legal aid clinics also addressed stigma and discrimination issues. The LACs initially catered to women only. They began responding to men’s cases subsequently.

PLHIVs were also informed about the government schemes at the legal aid centre. This study shows evidence of LACs assisting the PLHIVs in applying for a ration card, a crucial supporting document to access PDS and other schemes. A participant from Tamil Nadu shared that if the women didn’t have any identification like ration card or voter ID then they could apply for the pension from the central scheme directly by submitting a lawyer’s certificate from the LAC.

Applications for the scheme or petitions submitted through the legal clinic were promptly dealt with. The lead time to process the paperwork was reduced substantially and the schemes were reaching the PLHIVs within a shorter period. The figures in the table below suggest more than 50 percent settlement of both legal and non-legal cases.

<table>
<thead>
<tr>
<th>Legal Aid Clinic Performance in the Year 2009</th>
<th>Legal Cases</th>
<th>Non-Legal Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received</td>
<td>Settled</td>
<td>Received</td>
</tr>
<tr>
<td>432</td>
<td>217</td>
<td>1913</td>
</tr>
</tbody>
</table>

Source: [http://tansacs.in/Mainstreaminglegalaidclinics.html](http://tansacs.in/Mainstreaminglegalaidclinics.html) (as accessed on 12.3.2011)
Empowerment of positive people’s networks to deliver social protection schemes

Research studies indicated that among several reasons, cost of travel to the ART centre had caused PLHIVs to default in ART treatment. The Jatan project of Gujarat provides travel reimbursement to PLHIVs so that drug adherence improves. Positive results are visible in the forms of increased enrolment of children for the ART treatment.

This project is being handled by PLHIVs registered with GSNP+. This has not only created employment opportunities for PLHIVs in the State, but also built their capacities in handling accounts and preparing reports. This project is empowering the state level network in Gujarat to deliver a scheme and adapt it to suit the local needs of the community. (Refer to Case Study 4: Jatan Project of Gujarat – travel assistance, for more details).

**(Case Study 4: Jatan project of Gujarat – travel assistance)**

**Grant flow of the project:** Jatan project (since June 2008) is an initiative of the government of Gujarat. In this project, the Health and Family Welfare Department, via the NRHM, has made a grant available to Gujarat SACS. GSACS has channelised this grant to the state level network, namely Gujarat State Network for Positive People (GSNP+) to provide travel assistance to PLHIVs who come to the ART centres for ART drugs.

**Implementation:** A Jatan staff (a PLHIV registered with GSNP+) is deployed at each ART centre in Gujarat and assigned the task of getting travel forms filled and disbursing the travel money to PLHIVs who come to the ART centre. The Jatan staff are also expected to maintain accounts and submit the same to GSACS.

**Entitlement:** Jatan project reimbursed travel expenses by public transport (State Transport (ST) bus or train travel) from residence to ART centres upon submission of the ticket proof along with the travel allowance form. Auto fares or other modes of transport were not reimbursed. A PLHIV was expected to fill up the form each time he/she visited the ART centre to receive the money in the subsequent visit. In order to improve the enrolment of children in the ART centre, this project also provided travel reimbursement of an attendant along with an additional 100 rupees as compensation for the loss of wages for that day.

**Advantages:** Participants pointed out that the Jatan project has resulted in an increase in enrolment of children at the ART centre. Since the benefit could be availed at the ART centre itself, PLHIVs found the application process very convenient and issues related to confidentiality and disclosure were rendered redundant in this setting.

**Field level challenges:** PLHIVs from far off places used share-jeeps, carts etc. for travel to ART centre if the ST bus timing did not suit them. Others travelled by auto or personal vehicle (when public transport facility was not available). These persons could not produce tickets as proof and were denied the reimbursement. The 3 to 4 months delay to receive the travel reimbursement was embarrassing for those who borrowed money to travel to
the ART centre hoping to return the money the same evening. These delays also created doubts in the integrity of the scheme. GSACS officials however, viewed these constraints as teething problems in the pilot phase of the programme since staff needed guidance in maintaining accounts, auditing, compilation of data from all 20 districts undertaken by GSNP+.

Responding to field level challenges: A review meeting of GSNP+, GSACS and Gujarat NRHM authorities helped develop some new reimbursement rules to overcome the above challenges:

• PLHIVs will be expected to produce a ticket (either bus or train ticket) only for the first time when availing the benefit and will not be required later. That ticket amount will set the benchmark for all subsequent reimbursements. Alternatively, if one does not have a ticket, the Jatan staff will keep an updated ST fare chart for the reimbursements.
• PLHIVs who do not access public transport will receive flat 20 rupees travel assistance from the project.

A key informant from GSNP+ shared that they would be able to review these changes after one quarter to assess whether they successfully met the needs of PLHIVs.

Summary
The successful strategies discussed in this section highlight the endeavours of the positive people’s networks, SACS, NGOs and other stakeholders in addressing different needs of PLHIVs. Each state seems to have success stories that others can learn from or consider replicating in their states. Not just successes, but also the responses to the challenges offer learning points to others.

For example, Tamil Nadu and Orissa participants pointed out the need for bus travel concession as train routes were not extensive and unsuitable for short distance travel after ART medicines were available at the Link ART centres. Although Tamil Nadu has submitted a proposal for bus pass, it may want to learn from the challenges faced by Rajasthan and Gujarat in providing travel concession. Similarly, the legal aid clinics of Tamil Nadu have significantly contributed to the participation of men and women in social protection schemes in the state. Other states may want to consider similar clinics to address legal issues and stigma and discrimination related aspects.
Summary and Conclusions
This study has documented the facilitating and constraining factors in the uptake of State led social protection schemes by PLHIV in India. It has also presented some successful strategies through the use of case studies on experiences of implementation of schemes in the select states. Several stakeholders like positive people’s networks, NGOs, SACS, government Departments/ Ministries, the district administration and Panchayati Raj institutions have jointly collaborated to enable PLHIV access social protection schemes, thereby furthering the mainstreaming agenda of NACP - III. This has also contributed to the care and support strategy of the National AIDS Control Programme.

The process of accessing social protection schemes by PLHIV is at a nascent stage, wherein many PLHIV are making efforts to partake of them and gain from the benefits. Although much remains to be done to improve access to these schemes, the positive aspect is that the initiatives in this direction are fast gathering momentum.

Table 1: Summary of findings

Summary of findings
The study found an evidence of more than 25 different types of schemes (inclusive of state specific and central schemes) that cover broad categories, namely, travel concession, pension, food and nutrition, wage/ self employment, health, education of children, housing, crisis assistance and legal aid.

Key facilitating factors in the uptake of social protection schemes by PLHIV
- The positive people’s networks (PPNs), NGOs and SACS have been the force behind the uptake of social protection schemes by PLHIV. Each of these stakeholders has a comparative advantage and together their synergy has made access to social protection schemes a reality for PLHIV.
- Other stakeholders like the State Ministries/ Departments, the District Administration and the Panchayati Raj institutions also played a facilitative role through their commitment and cooperation.
- Assertive stand by users, PPNs and NGOs against discrimination and to demand services helped in the realisation of rights and entitlements of the schemes.
- Awareness and knowledge about social protection schemes helped initiate the right steps to participate in them and also demand the entitlements in cases of corruption.
- Governance related aspects like issuance of central/ state government orders made it possible for the users and PPNs to demand services/ benefits.
Key constraining factors in the uptake of social protection schemes by PLHIV

- Procedural issues like restrictive eligibility criteria, cumbersome application procedures, delays in receipt of benefit and opportunity costs either constrained PLHIV beneficiaries from participating in a scheme or affected the realisation of benefits accrued to them.
- Governance issues like corruption, leakages, lack of quality in services further exacerbated the constraints faced by PLHIV in accessing social protection schemes.
- HIV related stigma and discrimination (both real and perceived), resulting from the inevitable disclosure of one’s HIV status along the service delivery line impacted the utilisation by current users and prevented prospective users from coming forward to avail the different schemes.
- Gaps in certain livelihood and health insurance schemes constrained the effective utilisation of these significant schemes.
- Targeting and coverage of populations with BPL card constrained many HIV households who were poor but not necessarily in possession of the BPL card.
- Lack of sufficient data, including gender disaggregated data made analysis of utilisation patterns of social protections schemes difficult.

Successful strategies from different states that promoted the uptake of social protection schemes among PLHIV

- Special provisions within mainstream social protection schemes helped PLHIV gain entry without which they were unable to participate:
  - Relaxation in certain eligibility criteria of widow pension and Palanhar Yojana of Rajasthan,
  - Identification of HIV as chronic disease at par with cancer, TB, leprosy so as to extend similar provisions to PLHIV (Bus travel concession, Tabibi Sahay, MBPS, Palak Mata Pita Yojana)
  - Grant of conditional BPL status to gain entry into significant schemes like AAY, MMJR, KKT, etc.
  - Provision of additional benefits along with regular benefits within the same scheme (double nutrition through ICDS for malnourished children)
- Routing of schemes (like widow pension, travel assistance, Palanhar, Tabibi Sahay, MBPY, etc.) through the ICTC/ ART centre helped to reach the PLHIV getting registered/ visiting for follow up and provided a comfortable environment (less stigma and discrimination) for gaining knowledge and applying for schemes.
- Routing of schemes through the legal aid clinic (in the case of Tamil Nadu) helped to address legal issues, stigma and discrimination issues and hasten the application procedures for different schemes.
- Empowerment of positive people’s networks to deliver social protection schemes – Jatan project of Gujarat which is handled entirely by PLHIV from the State Level Network (form filling, maintenance of accounts, disbursal of travel money and report writing)

What emerges from the study is that the dynamics of responses vary across states which can be attributed to the commitment of the leadership of the State, SACS, networks and other stakeholders. Though there are similarities in the types of mainstream schemes being tapped, state level variations do exist. For example, in comparison to Tamil Nadu, Rajasthan and Gujarat, Orissa may want to consider responding through a wider range of schemes that cover education of children, uniform transport concession for travel to ART centres and health insurance schemes.
Suggestions and Recommendations

Some of the constraints, as shared by the participants of this study, like cumbersome application procedures, opportunity costs, delays in receiving the benefits, leakages, corruption, bribes, etc. are not new to social protection schemes. They validate similar findings of other research studies on performance of social protection schemes and Planning Commission reports of the GoI (Refer to Chapter One, review of select literature for more information). However, the positive people’s networks in each state have been able to navigate through these challenges to develop their own success stories (presented as case studies in Section 3.d) which other states could study and apply according to their local context.

HIV presents itself in different ways with needs of PLHIV varying across several parameters like gender, urban-rural variations and previous socio-economic conditions of the household. These needs help to form a framework of relevant responses in social protection at the national as well as the state level.

Participant’s perspective on priority needs of HIV households

Health, food and nutrition, livelihood, housing and schemes for higher education of children were viewed as priority areas for social protection. While health and nutrition needs received a primary preference among all participants, priority for other needs varied.

Livelihood which guaranteed a ‘dignified income’ per month so that they were not dependent on pension schemes of the government was perceived as a priority. Importance was also given to reservation of seats in higher education for children of PLHIV to secure their as is done for SC/ST students.

Another useful suggestion was to provide life insurance keeping in view the fact that ART was prolonging the lives of PLHIV.

Housing needs of the PLHIV in the urban areas also needed to be addressed considering the fact of steep house rents as a huge burden on the monthly expenses.

Suggestions and Recommendations

As discussed above, responses of different states have varied according to the local and several other factors, but there was a need for policy intervention at the national level to universalise some relevant schemes based on priority needs of PLHIV to bring a level of parity in the benefits received by PLHIV across the states.

The study proposes the following broad recommendations with a view to address the priority social protection needs of PLHIV and to reduce the constraints faced by users and consequently improve the uptake of such schemes. The recommendations are woven around the following points:

- Social protection for HIV households through a package of schemes
  - Basic package of schemes
  - Basic plus package of schemes
  - Delivery of the basic and basic plus package of benefits as a cumulative amount via the ICTC/ART/LACs in the state
• Increase knowledge and awareness about schemes
  ♦ Use of print media
  ♦ Use of electronic media
  ♦ Maximise the scope of ICTC/ ART/ Link ART centres

• Address procedural constraints
  ♦ Review of eligibility criteria
  ♦ Review the supporting documents required
  ♦ Cash transfers to bank accounts

• Address stigma and discrimination
  ♦ Through sensitisation of government staff at all delivery points
  ♦ Capacity building of SLNs/ DLNs
  ♦ Treating HIV as chronic health condition

• Governance related aspects
  ♦ Build synergies between PPNs and NGOs
  ♦ Stakeholder consultation meetings
  ♦ Central government orders for special provisions
  ♦ Government order to percolate to all in the service delivery chain

• Documentation, research and training
  ♦ Data Management
  ♦ Implications for future research
  ♦ Implications for future training for effective implementation and delivery of social protection schemes

Social protection for HIV households through a package of schemes

Rationale
HIV Households cope with risks by reducing consumption on essential items including food, borrowing from moneylenders (often at very high interest rates), extended hours of work by women and children or a complete dependence on other family members or NGOs.

The HIV epidemic has seen the conversion of yesterday’s poor into today’s hardcore poor and yesterday’s non-poor into today’s poor. BPL surveys are likely to leave out these ‘newly poor’ households because assessment of such households is possibly done in the pre-crisis situation. Such households remain out of coverage of the poverty alleviation programmes targeted to BPL families (although grant of the conditional BPL status helped PLHIV access certain schemes in some states).

Based on risks faced by HIV households and the study participants’ perspectives on social protection needs, this study suggests social protection for HIV households through a package of schemes that will reduce the risks and improve coping mechanisms of such households.

1The concept of minimum social security (for the unorganised workers) is present in the Unorganised Workers’ Social Security Act, 2008, prepared by the National Commission for Enterprises in the Unorganised Sector (NCEUS).
**Basic minimum package**
The basic minimum package for all HIV households could cover health related schemes (especially health insurance) and food and nutrition schemes. These two categories of schemes are likely to reduce the household burden of medical expenses and also ensure a minimum intake of food. HIV households that are comparatively better resourced may find themselves prevented from sliding down further.

**Health related schemes**
The free ARV roll out plan coupled with concession/ assistance in travel to ART centre reduced health related expenses substantially.

Schemes like the Star Health Insurance and KKT (Tamil Nadu) and MMJRK (Rajasthan), are strides in the direction of health insurance by the State for the PLHIV. States who have yet to provide health coverage to HIV households could explore similar schemes or tap other existing schemes like the Rashtriya Swasthya Bima Yojana of the Ministry of Labour and Employment, GoI, which provides coverage to BPL households from financial liabilities arising out of health shocks.

**Food and nutrition schemes**
PLHIV in all the four states received foodgrains from the TPDS and AAY (ICDS and MDM mainly reaching out to children). Both are major food security schemes in India, but constraints in the form of quality and quantity of foodgrains affected their efficiency. What remains to be seen is the implementation of the newer provisions like food stamps or coupons, choice of Fair Price Shops (FPSs) and the biometric identification system to improve targeting and quality of services.

However, PLHIV especially those on ARTs are unable to access the often advised extra nutritious food like fruits and milk or other sources of high protein to cope with the toxic side effects of the drugs through existing food security schemes. Through Tabibi Sahay, the Gujarat Government offers a direct cash transfer to purchase nutritious food. Tamil Nadu too has submitted a proposal to the state government for consolidated food packets for comprehensive nutrition for women and transgenders. A deliberation among different stakeholders, for the delivery of a comprehensive nutritional package either through mainstream food security schemes or through target schemes by the National AIDS Control Programme, is hereby suggested.

**Basic plus package**
HIV households (especially women, youth, children, destitute men, socially excluded groups like sex workers, transgenders, MSMs and IDUs), facing multiple deprivations need additional social assistance. This can come in the form of cash transfers (both conditional and unconditional) to ensure a basic survival, livelihood options (to make them more self-reliant and reduce dependency on cash transfers), insurance schemes and housing options (especially for those facing desertion).

With a focus on self-reliance, Gujarat state encouraged widows below the age of 40 years and having children below the age of 22 years, to receive vocational training for income generation, (e.g. tailoring) so that they were self reliant and widow pension could be eventually stopped.
The training was given within two years of the spouse’s death and a letter was sent asking the woman to report for the training. Assistance was provided to start a business by granting a small amount upto Rs. 3000.

**Schemes offering cash transfers**
Access to the recurring cash transfer schemes like the widow pension, old age pension, MBPS (Orissa) and non-recurring/ one time grants like the NFBS, Chief Minister’s Relief Fund (Orissa), distress relief fund for funeral expenses (Tamil Nadu), etc could be enhanced with the removal of procedural constraints, middle men and bribe payments. There was also need to consider raising the widow pension amount keeping in view the rising inflation.

Conditional cash transfer schemes like the PalanharYojana (Rajasthan), Palak Mata PitaYojana (Gujarat) provided cash assistance to households on condition of education of children. Special provisions in PalanharYojana for all children in HIV households significantly helped in taking care of the education expenses. It also helped to ensure that children were not withdrawn from school to reduce household expenses. Similar schemes can be considered in all states to aid the continuation of schooling of children.

JSY, also a conditional cash transfer scheme was useful for safe and institutional deliveries. Sensitisation of all health care providers in primary, secondary and tertiary hospitals to reduce discrimination along with provision of required resources for taking universal precautions and PEP would increase the utilisation of this scheme.

**Livelihood schemes**
A wage employment scheme like MGNREGA has the advantage of a substantial cash transfer benefit in lieu of public works. But, this scheme is helpful to PLHIV in rural areas and those capable of doing manual labour. Specials provisions to be assigned ‘light jobs’ like serving water, managing the crèche have been useful for PLHIV, but, these experiences were replete with disclosure and discrimination issues which need to be addressed.

SHGs have been useful for developing a revolving fund (especially in Tamil Nadu), but overall, SGSY and SJSRY remain underutilised in terms of providing income generation activities. Studies on viable economic activities for PLHIV need to be conducted in partnership with the MoRD to initiate suitable livelihood programmes. There is also a need to reach out to the urban and semi urban PLHIV who remain uncovered by MGNREGA.

Some networks are making inroads in developing income generating activities (for example, RNP+ through its Centre for Learning and Rehabilitation (CLR) in Jaipur, Rajasthan; Aadhar project by the Ahmedabad district level network), but these are mostly funded by private or corporate donors. (Gujarat has tapped its huge NRI population to overcome the constraint of lack of funds). These projects would however need to be studied to understand their viability, sustainability and possibility of replicating them in other districts or states.

**Other insurance schemes**
There was no evidence of uptake of other insurance schemes by PLHIV, mainly because they found themselves excluded from the life insurance policy due to their HIV status. Insurance
schemes like the Aam Aadmi Bima Yojana or the Jan Shree Bima Yojna (proposed by the Unorganised Workers Social Security Act, 2008) could be considered for PLHIV too to provide a sense of security for old age or crisis situation resulting from death of breadwinner.

**Housing schemes**

Housing was a crucial requirement especially for women living with HIV. The centrally sponsored Indira Awas Yojana offered land and a substantial cash transfer to build a house or convert a *kaccha* house into a *pucca* house (only in rural areas). Tamil Nadu participants were able to utilise this scheme with the help of legal aid clinics in the state. Orissa had the Mo Kudiya scheme which also provided a cash transfer to build a house and there was evidence of PLHIV accessing this benefit.

Preference in low cost housing or other shelter schemes in urban areas for migrating PLHIV would help them cope with the high costs of urban living.

**Delivery of the basic and basic plus package of benefits as a cumulative amount via the ICTC/ ART/ LACs in the state**

Once the application form of the package schemes for the eligible PLHIV was approved, the funds for the same from different government departments could be routed through the SACS. The SACS could disburse the money as a cumulative package through the ICTC/ ART/ link ART centres/ legal aid clinics in a state. Alternatively, the disbursal could be through the DLN office if there was insufficient coverage of the districts through the ICTC/ ART/ Link ART centres. This would not only help to offer a cumulative package of benefits, but would reduce stigma and discrimination issues resulting from the disclosure of HIV status at different points in service delivery. This arrangement could be tested on a pilot basis to begin with. (The Jatan project of Gujarat that draws money from the NRHM to provide cash assistance for travel to ART centre is following a similar model – Refer to Section 3.d on Successful strategies for details).

**Combinations of cumulative package of benefits**

However, this cumulative package of benefits refers to recurring cash transfers only. Given the wide variations in the eligibility criteria and the entitlements of different schemes, a uniform inter-State or intra-State cumulative package of benefits may not be viable. Instead, different combinations of cumulative package of benefits are possible. For example, in Gujarat, WLHIVs residing in rural areas can avail of recurring cash transfers in widow pension, Tabibi Sahay and MGNREGA to have an annual income of Rs. 22,960. But a widow from an urban household in Gujarat may be able to avail only widow pension and Tabibi Sahay to receive an annual income of Rs. 12,000 only.

Similarly, in Rajasthan, a widow living with HIV and two school going children may receive widow pension and PalanharYojana which will bring an annual cash transfer of Rs. 24,200/-.

A PLHIV from a rural household in Orissa availing of MGNREGA and Madhu Babu Pension

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2There are marked variations in the schemes according to target audience, that is, schemes targeted to women only (widow pension), rural households only (NREGA, IAY SGSY) or BPL households only (AAY, IAY, NFBS, SGSY, SISRY, MMIRK), entitlements are not recurring, but a onetime grant (NFBS, JSY), schemes only for PLHIVs on ART (Tabibi Sahay, Travel concession) or other state wise variations.
scheme may receive an annual income of Rs. 12,400/-. A widow from rural Tamil Nadu will receive an annual of Rs. 16,000/- only from MGNREGA and widow pension.

A word of caution here is that MGNREGA being a conditional cash transfer scheme, systems (like an attendance card) would need to be put in place to ensure that money was transferred to the PLHIV after having worked on the job site as per the provisions of the scheme.

Increase knowledge and awareness about schemes

Use of print media
The positive people’s networks and NGOs could begin to compile the schemes, the entitlements and the application procedure in their respective states. States that have already initiated such work could prepare booklets, pamphlets and displays at strategic locations in regional language to create awareness about schemes. Additionally, the government departments should be encouraged to display information about their schemes in their office premises. (Refer to Annexure 3 for an example on user friendly flipchart on ‘how to avail a scheme’)

Use of electronic media
Apart from print media, air slots on radio and television would be useful to spread awareness about schemes like the case of Madhu Babu Pension scheme in Orissa. This would also help to penetrate populations not registered with the networks or ICTC/ ART centres.

Maximise the scope ICTC/ ART centres
ICTC/ ART counsellors could be trained in helping PLHIV apply for social protection schemes. However, this entailed considerable amount of work. A feasibility study based on the workload assessment of ICTC/ ART counsellors should guide this decision.

Alternatively, support in the form of additional staff, possibly a DLN member with office space in the ICTC/ ART centre could prove useful to maximise the scope of their outreach. A similar model is being followed by Jeevandeep project of Gujarat. Tamil Nadu’s legal aid clinics in the ICTC centres in select districts have also had a positive impact in guiding PLHIV to access the scheme.

Routing the schemes through the ICTC/ ART centres was a successful strategy for easier outreach to PLHIV, especially those who were not registered with the networks. It also offered a comfortable environment to PLHIV as there was reduced fear to disclosure of one’s HIV status. If the ICTC/ ART centres became a one-stop-shop for applying and receiving the benefits of schemes, then follow up for ART treatment would probably increase. A PLHIV would come under the scanner of the ART counsellor on a regular basis and this could positively impact drug adherence also.

Address procedural constraints

Review of eligibility criteria
There was evidence of relaxation in the eligibility requirements when positive people’s networks, NGOs and SACS advocated with the relevant government department regarding the same.
Eligibility criteria needed to be revised to make them ‘inclusive’ for users rather than exclusive. The criterion of minimum annual income varied across states (Rs. 24000 to 36,000 p.a.) and needed to be increased in keeping with current levels of income.

**Review the supporting documents required**
To reduce the burden of collecting different types of documentary evidence, the ART diary was deemed to be a comprehensive document that proved one’s HIV status, providing information about ART medication, age, sex and the residential address.

It was essential to seek easier alternatives for specific proofs related to age, identity and residence so that the screening was not compromised. For example, marksheet of a child instead as a proof of schooling instead of a bonafide certificate from the school principal.

**Cash transfers to bank accounts**
A uniform system of cash transfer to bank accounts was desirable to reduce leakages and disclosure, but may not possible in places where there were no banks or they were located far away. Wherever possible, users should be encouraged and trained in accessing their bank accounts.

**Address stigma and discrimination**

**Through sensitisation of government staff at all service delivery points**
Although sensitisation of officials of key government ministries/ department was an ongoing agenda of mainstreaming initiatives in each state, it needed to percolate to all staff at the service delivery points in order to reduce discrimination issues. Adequate dissemination of the information at critical places like Collectorate, Gram Panchayats, anganwadis, bus depots, ration shops, health care set ups, etc was needed.

**Through capacity building of SLNs/ DLNs**
Capacity building through workshops on assertive communications skills and rights framework, for SLN/ DLN members would help them to deal/ stand up against discrimination. Systemic issues like corruption would need to be addressed through policy change. Assertiveness training to help PLHIV to fight corruption was also essential.

**Colour code for HIV as chronic health condition**
In the case of bus pass of Rajasthan, a single colour code of the card for health related categories like cancer and HIV/ AIDS, and avoiding use of the identification of these illnesses could make it disclosure proof’.

**Governance related aspects**

**Build synergies between positive people’s networks and NGOs**
The politics of AIDS funding has led to a gap between NGOs and PPNs, since they compete for the same resources. However, both have specific skills and limitations. Capitalising on skills of each other to create a synergy will lead to a positive atmosphere of learning and sharing among all players.
Stakeholder consultation meetings
Stakeholder consultation meetings that involve the relevant government department, SACS, PPNs and NGOs will go a long way in strategy building and addressing procedural issues in the implementation of schemes.

Central government orders for special provisions
Government orders prescribing special provisions for PLHIV in central schemes (similar to the railway concession or AAY) were desirable since they reduced state level efforts for mainstreaming and hastened implementation.

Government order to percolate to all in the service delivery chain
Communication about the government orders specifying special provisions for PLHIV should reach all officials to the lowest denomination, involved in the delivery of service.

Documentation, research and training

Data Management
There was a need to develop systems for data collection on uptake of each scheme by PLHIV which should include gender disaggregated information as well. Though this data may be available at the district level with the DLNs/ SLNs it was not collated at the state level. It would be desirable to have this data available on the website of the respective SACS for easier access.

Implications for future research
Most at risk populations like MSM, transgenders, sex workers, IDUs were not adequately represented from all states in this study. Anecdotal evidence from Gujarat showed how MARPs faced challenges because they often lived in non-traditional family set-ups and did not have documents like ration card, voter’s identity card, and income certificate and so on which were prerequisites to apply for schemes. There was a need for further research to study their specific problems to inform suitable interventions for social protection for MARPs.

This study has captured the experiences in accessing social protection schemes by PLHIV registered with the state or district level networks. A significant section of the users were engaged in outreach work of the networks which increased their networking abilities and positively impacted the access to schemes. An in-depth study with PLHIV not registered with the networks is desirable to understand the challenges faced them accessing the schemes.

This being a qualitative study provides overall trends in factors that have facilitated or constrained the utilisation of social protection schemes by PLHIV in select states of India. The study has also identified some successful strategies based on the experiences of accessing schemes in these states. However, quantitative studies that entail household surveys are desirable to further understand the impact of the social protection schemes on poverty alleviation of HIV households.
Implications for future training for effective implementation and delivery of social protection schemes

Capacities of the positive people’s networks’ staff, NGOs and government staff involved in delivery of social protection schemes needed to be built in data management, implementation of social protection schemes and protecting the rights of the PLHIV against stigma and discrimination for better management and effective delivery of schemes.

Link workers, ASHA, ANMs are a pool of trained personnel who could be involved in the information dissemination process (similar to the experience of Tamil Nadu) and also in the service delivery chain of social protection schemes for PLHIV and the general population.

Training of local governance structures such as the PRIs and the district administration for creating awareness and support regarding the proper implementation of social protection schemes and protecting the rights of the PLHIV against stigma and discrimination would also contribute to the overall effective delivery of social protection schemes.

Overall it is recommended, that there be proactive responses that seek to facilitate the participation of PLHIV in the social protection schemes through policy provisions and government orders, to build an enabling environment where PLHIV do not fear about disclosure and discrimination while accessing schemes and to create greater awareness among PLHIV not just about the schemes and application procedures, but to be assertive to demand services and benefits from the service delivery system so that they become more accountable to the users.

The networks, NGOs and SACS may need to align their advocacy strategies regarding social protection schemes for PLHIV in line with the ongoing right to food campaign, right to education and the Aadhar UID project to address food, nutritional and educational requirements of HIV households.
**Information on Social Protection Schemes in India**

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<thead>
<tr>
<th>No.</th>
<th>Name of Scheme</th>
<th>Initiation</th>
<th>Entitlement</th>
<th>Target Group</th>
<th>Implementing Agency</th>
<th>Special features</th>
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<tr>
<td></td>
<td><strong>Pension Schemes</strong></td>
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<td>* Concerned state government is also urged to provide the equal or more amount to the person.</td>
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<td>1</td>
<td>Indira Gandhi National Widow Pension Scheme (IGNWPS)</td>
<td>Feb 2009</td>
<td>Rs. 200 per month per beneficiary</td>
<td>Widows aged between 45 and 64 years of age from BPL household</td>
<td>MoRD, GoI. The Gram Panchayats/Municipalities are expected to identify the beneficiaries under the scheme.</td>
<td>* Pension is to be credited into a post office or public sector bank account of the beneficiary.</td>
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<td>* The pension will be discontinued if there is the case of remarriage or once the widow moves above the poverty line.</td>
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<td>* The state and Union Territories are required to furnish a certificate that all eligible widows have been covered under the scheme.</td>
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<tr>
<td>2</td>
<td>National Old Age Pension Scheme (NOAPS)</td>
<td>August 1995</td>
<td>Rs.75/- per month per beneficiary</td>
<td>Destitute aged 65 and above</td>
<td>100 per cent Central assistance, implemented by the Panchayats and Municipalities</td>
<td>* All benefit payments should preferably be payable to the bank account of the beneficiary in the Post office Savings Bank or in a commercial bank or through Postal Money Order. However, in the case of NOAP cash disbursement may be permitted provided the payment is made in public meetings preferably of Gram Sabha in village and in neighbourhood/ mohalla committees.</td>
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<td>* The benefit under NOAPS should be disbursed, in not less than two installments.</td>
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<td>Upto Rs. 100 per month</td>
<td>Lifelong monthly pension scheme for old, widows or a destitute</td>
<td>Money to be received from the Gram Panchayat Headquarters</td>
<td>in a year and if possible the benefit may be disbursed in more installments as per directions of the State Government.</td>
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</table>
| 3   | Other Pension Schemes - old age pension, widow pension, | Feb 2008 | lifelong monthly pension Rs. 200/- per month | Elderly, disabled, widows. Includes widows of PLHIV or any PLHIV, irrespective of age. | OSACS with the district machinery | Eligibility Criteria:  
- A person has to be 60 years old (in case of NOAP it is 65)  
- For a widow there is no age restriction but she should be of 18 years old.  
- He has to be a destitute and no other source of income.  
- The annual income should not exceed more than Rs.3,200/-  
- Should be a permanent resident of a village.  
- Should not have been assisted by any other Social Assistance Scheme.  
- Should not have been convicted in any court of law. |
<p>| 4   | Madhu Babu Pension Scheme (MBPS) (ONLY in Orissa) |                       |              |                |                     | No physical verification of PLHIVs required — consent for inclusion of a positive person is taken at the ICTCs during post-test counseling, after which the list of names and addresses of persons who have agreed to receive the pension are sent to OSACS, for entering into a database and forwarding, after collation, to respective District Collectors. The Collectors then forward the list to respective Block Development Officers (BDOs), who would then send the pension amount of Rs. 200 in the form of an account payee cheque to the address of the PLHA. This has been designed so that the PLHAs. |</p>
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<tr>
<td>5</td>
<td>Targeted Public Distribution System (TPDS)</td>
<td>Since 1951</td>
<td>rice, wheat, sugar and kerosene at very subsidised rates</td>
<td>BPL and APL families as recognized by the Gram Sabhas or other competent authority.</td>
<td>Joint responsibility of the Central and the State Governments.</td>
<td>Confidentiality is protected at all times, and there is no need for the recipient to come in person for verification or disbursement. However, it does come under the concept of ‘shared confidentiality’ and beneficial disclosure.</td>
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<td>6</td>
<td>Antyodaya Anna Yojana (AY)</td>
<td>2000</td>
<td>35 Kg rice (@Rs 3) or wheat (@Rs 2) per month. (part of the PDS - for destitute families)</td>
<td>1. A family or individual who is. infirm, disabled, destitute men &amp; women, i. widows, old persons (above 60); ii. primitive tribes.</td>
<td>Through the PDS</td>
<td>Consumers can buy the foodgrains through the network of Fair Price Shops which are there throughout the state. Possession of ration card is must. The ration card carries a colour code to distinguish between BPL and APL and AAY households based on which the amount of ration is available to the household.</td>
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<td>7</td>
<td>Integrated Child Development Scheme (ICDS)</td>
<td>Since Oct 1975</td>
<td>Supplementary feeding given at aanganwadi, other benefits like health monitoring, etc.</td>
<td>2. Pre-school children (0 to 6 years), adolescent girls, pregnant and lactating women</td>
<td>centrally sponsored, state governments contribute 50% of the costs of supplementary nutrition (i.e. Re. 1 per child per day)</td>
<td>This scheme provides a range of services like supplementary nutrition, health check-up, immunization, referral services, and non formal preschool education to children upto the age of six as well as nutrition of adolescent girls and pregnant and nursing women. The ICDS centres or Anganwadi is the centre of convergence of all the</td>
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<td>8</td>
<td>Mid-day meal (MDM) Scheme</td>
<td>A fresh cooked meal on each working day — at least 200 days an year.</td>
<td>3. All children in government and aided primary schools</td>
<td>Central and state govt.</td>
<td>The Government of India contributes to the mid day meal scheme in the form of supply of free foodgrain (@ 100 grams per child per day) and a contribution of Rs. 1.50 per child per day towards cooking costs provided the State Government/UT Administration</td>
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| 9   | Annapoorna Yojna | 10 kg rice free of cost | 4. Destitute person | Through the PDS | The selected person will get 10 Kgs of rice from the Gram Panchayat Secretary at free of cost Eligibility Criteria:  
- The person should be a helpless and destitute  
- The person should be a minimum of 25 years old. |
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| 10  | Tabibi Sahay (Only in Gujarat)     |            | Cash transfer of Rs. 500 per month | Person suffering from TB, leprosy, cancer, PLHIVs on ART | Gujarat Dept. of Social Justice and Empowerment          | - The applicant should be a resident of Gujarat since 1978.  
- The annual income of the applicant should not be more than Rs. 15,977 per annum if hailing from rural areas, and not more than Rs. 21,205 per annum, if hailing from urban settings.  
- The applicant should not be from the SC/ST category  
- The applicant should be socially and economically backward  
- If a PLHIV has already been accessing this scheme for TB or cancer or leprosy, then application for HIV is rendered inapplicable. |
|     |                                    |            |                              |                                                         |                                                          |                                                                                                                                                                                                                  |

**Wage/Self Employment Schemes**

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<th>No.</th>
<th>Name of Scheme</th>
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<th>Target Group</th>
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<tr>
<td>11</td>
<td>Mahatma Gandhi National rural Employment Guarantee Act (MG-NREGA)</td>
<td>Feb 2006</td>
<td>Rs. 100 per day for 100 days</td>
<td>Any person who is above the age of 18 and resides in rural areas is entitled to apply for work.</td>
<td>Gram panchayats, district panchayats, line departments (PWD, Forest Dept.) and NGOs. A Programme Officer is responsible for the implementation of NREGS at the block level.</td>
<td>1. Secures livelihood by guaranteeing 100 days of wage employment in a financial year to a rural household whose adult members volunteer to do unskilled manual work. Timely payment: Workers are to be paid weekly, or in any case not later than a fortnight. Payment of wages is to be made directly to the person concerned in</td>
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| 12  | Swarna-jayanti Gram Swarojgar Yojana (SGSY) | April 1999 | Bank credits and subsidy by government. | Families Below the Poverty Line (BPL) in rural areas. | SGSY is being implemented by the District Rural Development Agencies (DRDAs), with the active involvement of Panchayati Raj Institutions (PRIs), the Banks, the Line Departments and the Non-Government Organisations (NGOs). | the presence of independent persons of the community on pre-announced dates.  
2. Unemployment allowance: If work is not provided within 15 days, applicants are entitled to an unemployment allowance: one third of the wage rate for the first thirty days, and one half thereafter.  
3. Worksite facilities: Labourers are entitled to various facilities at the worksite such as clean drinking water, shade for periods of rest, emergency health care, and child-minding.  
SGSY focuses on social mobilisation of the poor to build their own Self-Help Groups (SHGs). A SHG may consist of 10-20 persons belonging to BPL families and a person should not be a member of more than one group. In the case of minor irrigation schemes and in the case of disabled persons, this number may be a minimum of five (5).  
It is necessary to take up the right activity. For this purpose, 4 to 5 activities are selected in each Block with the help of officials, non-officials and the Bankers. These are called ‘Key Activities’, and should be such that they give the Swarozgaris an income of Rs. 2000 per month, net of Bank loan repayment.  
Subsidy is uniform at 30% of the project Cost subject to a max of Rs. 7500/-. For SCs/STs, the subsidy is 50% |
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<td>of the project cost, subject to a max Rs. 10,000/ For groups of Swarozgaris, the subsidy is 50% of the cost of the scheme, subject to a ceiling of Rs. 1.25 lakh. There is no monetary limit on subsidy for irrigation Projects. Subsidy is back ended i.e. it is released as part of the loan to be adjusted against last instalments on satisfactory utilisation of the loan for the micro enterprise. No interest is charged on the subsidy amount.</td>
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<td>14</td>
<td>Livelihood opportunities through other welfare schemes</td>
<td>Individual or group economic activities</td>
<td>SC/ ST individuals</td>
<td>Varied corporations</td>
<td>Tamil Nadu Adi Dravidar Housing Development Corporation (TAHDCO) has economic development schemes for SC/ STs. PLHIVs approached TAHDCO for loans for individual or group economic activities. In Gujarat, there was Ghar Divda Scheme (micro enterprise scheme), a component of welfare schemes for SCs. This scheme offered loans to individuals with relevant skills for micro-enterprise.</td>
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<td>15</td>
<td>Indira Awas Yojana</td>
<td>Since 1985–86 linked to RLEG and JRY Independent scheme since 1996</td>
<td>Rs.45,000/- per unit for plain areas &amp; Rs.48,500/- for hilly areas - new construction of house. -For upgradation of kutch house to pucca - Rs.15,000/- -Provides homestead sites to rural BPL HHs who landless</td>
<td>People BPL line living in rural areas belonging to Scheduled Castes/ Scheduled Tribes, freed bonded labourers and non-SC/ST. (also reservation for ex-servicemen and disabled persons BPL</td>
<td>Flagship scheme of the Ministry of Rural Development implemented by District Rural Development Agencies (DRDAs) / Zilla Parishads on the basis of allocations made. The Gram Sabha will select the beneficiaries</td>
<td>The order of priority for selection of beneficiaries amongst target group below poverty line is as follows: (i) Freed bonded labourers (ii) SC/ST households who are victims of atrocities (iii) SC/ST households, headed by widows and unmarried women. (iv) SC/ST households affected by flood, fire, earthquake, cyclone and similar natural calamities. (v) Other SC/ST households. (vi) Non- SC/ST households. (vii) Physically handicapped. (viii) Families/widows of personnel of defence services / para-military forces, killed in action. (ix) Displaced persons on account of developmental projects, nomadic seminomadic and de-notified tribals, families</td>
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<td>16</td>
<td>Mo Kudiya housing scheme (only in Orissa)</td>
<td>Financial assistance for constructing a house</td>
<td>5. Poor households in Orissa not identified as BPL</td>
<td>MoRD, Orissa</td>
<td>This is a low cost housing scheme for the people denied houses under the IAY programme. This scheme is administered at the district collector level. The entitlement amount is in the range of Rs. 25000 to 35000. The grant is received in the form of cheque from the BDO office and in installments of Rs. 10000.</td>
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<td>17</td>
<td>Kalaignar Veetu Vasathi Thittam' (KVVT) (only in Tamil Nadu)</td>
<td>Thatched roof house converted to pucca house</td>
<td>6. Rural households</td>
<td>MoRD, Tamil Nadu</td>
<td>In this scheme, the hutments or kachha houses with thatched roofs were converted into pucca houses. The procedure for implementing this scheme included a survey conducted by the Panchayat president along with the BDO.</td>
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**Health Related Schemes**

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<th>No.</th>
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<tr>
<td>18</td>
<td>Janani Suraksha Yojana</td>
<td>Since 2003</td>
<td>Rs. 1,000 as incentive for institutional delivery – for upto 2 live births</td>
<td>7. Pregnant women above 19 years from BPL households</td>
<td>Through the NRHM</td>
<td>JSY integrates help in the form of cash with antenatal care during pregnancy period, institutional care during delivery as well as post-partum care. This is provided by field level health workers through a system of coordinated care and health centers. In 2006, the Tamil Nadu JSY scheme was modified into a maternity support scheme to provide a cash assistance of Rs. 6,000.</td>
</tr>
<tr>
<td>No.</td>
<td>Name of Scheme</td>
<td>Initiation</td>
<td>Entitlement</td>
<td>Target Group</td>
<td>Implementing Agency</td>
<td>Special features</td>
</tr>
<tr>
<td>-----</td>
<td>----------------</td>
<td>------------</td>
<td>-------------</td>
<td>--------------</td>
<td>----------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>19</td>
<td>PSI Star Health Insurance Scheme</td>
<td>Since 2008</td>
<td>Health coverage up to a fixed amount in empanelled hospitals</td>
<td>8. PLHIVs</td>
<td>Star Health and Allied Insurance Company and PPNs and NGOs</td>
<td>The policy is a group insurance having two criteria – 200 members in each group and CD 4 count of 300 at the time of enrollment. The premium for this cash-less hospitalisation scheme is fixed at Rs. 1,500 per annum. But PSI has been able to subsidise the premium so each of the insured has to pay Rs. 755. There is no age limit for the eligibility and the policy does not cover anti retro viral treatment, tuberculosis and gastroentitis, which are already taken care of by the public health system. The insurance provides Rs. 15,000 for hospitalisation at any government hospital and another Rs. 15,000 if the person is confirmed with full-blown AIDS. It also covers funeral expenses.</td>
</tr>
<tr>
<td>20</td>
<td>Kalaignar Kapitu Thittam (Only in Tamil Nadu)</td>
<td>July 2009</td>
<td>Health coverage (including surgeries)</td>
<td>9. BPL households</td>
<td>Tamil Nadu State govt and star Health and Allied Insurance Company</td>
<td>People who have an annual income of less than Rs. 72,000 stand eligible for KKT. It provides cashless transaction insurance for a host of identified high-cost medical contingencies needing surgical care and hospitalisation (in empanelled hospitals). The entire insurance premium of Rs. 1,00,000 for a family for 4 years is paid by the State government. The insured person can avail up to Rs. 2.5 lacs for the cost of operations. Around 31 types of surgeries are covered under this scheme.</td>
</tr>
<tr>
<td>No.</td>
<td>Name of Scheme</td>
<td>Initiation</td>
<td>Entitlement</td>
<td>Target Group</td>
<td>Implementing Agency</td>
<td>Special features</td>
</tr>
<tr>
<td>-----</td>
<td>----------------</td>
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<td>--------------</td>
<td>---------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>21</td>
<td>Mukhya Mantri Jeevan Raksha Kosh (MMJRK) (Only in Rajasthan)</td>
<td>Dec 2009</td>
<td>Free medical treatment in government hospitals</td>
<td>10. BPL households including PLHIVs</td>
<td>Department of Medical, Health and Family Welfare, Rajasthan</td>
<td>MMJRK is an insurance scheme to provide free secondary and tertiary health services through the government health system. Under this scheme, free OPD and IPD care is provided to BPL families in all public health care settings. Under this scheme, all medicines and/or implants needed for the treatment as well as the follow up treatment was provided by health facilities at state, district or sub district level.</td>
</tr>
</tbody>
</table>

**Education Schemes for Children**

<table>
<thead>
<tr>
<th>No.</th>
<th>Name of Scheme</th>
<th>Initiation</th>
<th>Entitlement</th>
<th>Target Group</th>
<th>Implementing Agency</th>
<th>Special features</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>Palanhar Yojana (Rajasthan)</td>
<td></td>
<td>Rs. 500 per month to guardians of children below 5, Rs. 675 for children above 5 and Rs. 2,000 per year for books and uniform</td>
<td>11. Destitute children, since April 2101, included all children of HIV household</td>
<td>Ministry of Social Justice and empowerment, Rajasthan</td>
<td>Palanhar Yojana aims to provide care to destitute children through close relatives who are called their Palanhar (guardian). This scheme is applicable till the child turns 15 years old. The process of availing the scheme involves a duly filled application form with several supporting documents, namely: photocopy of the bread winner’s ART diary, children’s school bonafide certificate, their birth certificates, children’s and parents photographs, parent’s ID proof, income certificate (with income not more than Rs. 36,000 per annum). Along with a letter certified by the Sarpanch that the parents were bringing up the children and no one else, it was submitted to the social welfare department.</td>
</tr>
<tr>
<td>23</td>
<td>Palak Mata Yojana (Gujarat)</td>
<td></td>
<td>cash assistance of Rs. 1000 per month</td>
<td>12. orphaned or destitute children in Gujarat</td>
<td>Ministry of Social Justice and empowerment, Gujarat</td>
<td>Palak Mata Pita Yojana of Gujarat is a scheme for cash assistance providing to the guardian to meet the educational and nutritional</td>
</tr>
<tr>
<td>No.</td>
<td>Name of Scheme</td>
<td>Initiation</td>
<td>Entitlement</td>
<td>Target Group</td>
<td>Implementing Agency</td>
<td>Special features</td>
</tr>
<tr>
<td>-----</td>
<td>-----------------------------------------------------</td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>needs of the child. The guardians minimum annual income should not be less than Rs. 60,000.</td>
</tr>
<tr>
<td>24</td>
<td>Orphans and Vulnerable children Trust (OVCT)</td>
<td></td>
<td>Cash assistance of Rs. 3,000 to 5,000 per year</td>
<td>13. Children affected by AIDS</td>
<td>Tamil Nadu State Govt and TANSACS</td>
<td>OVCT is a scheme designed by Tamil Nadu SACS to provide financial assistance to AIDS orphans and vulnerable children. The chief minister of Tamil Nadu had arranged for a sum of Rs. 5 crores for this trust. The interest earned out of this corpus fund was used to provide a cash transfer of Rs. 3,000 to 5,000 per annum to orphans and vulnerable children to meet their educational and nutritional needs.</td>
</tr>
</tbody>
</table>

### Crisis Assistance Schemes

<table>
<thead>
<tr>
<th>No.</th>
<th>Name of Scheme</th>
<th>Initiation</th>
<th>Entitlement</th>
<th>Target Group</th>
<th>Implementing Agency</th>
<th>Eligibility Criteria</th>
</tr>
</thead>
</table>
| 25  | National Family Benefit Scheme                      | August 1995| A lump sum amount of Rs. 10,000/-               | 14. BPL Families who have lost their primary bread winner |                    | • The deceased person should be a BPL Category.  
• The deceased person should be the earning member of the family.  
• The deceased person should be in between 19 to 64 years of age.  
• The claimant should produce a death certificate duly issued by Medical Officer of concerned PHC.  
• Should not have received any post death benefit assistance from any other Insurance Company.  
Along with the application form, women had to submit ration card, spouse’s death certificate, income certificate and signatures from village panchayats.  
<pre><code>                                                                                      |
</code></pre>
<table>
<thead>
<tr>
<th>No.</th>
<th>Name of Scheme</th>
<th>Initiation</th>
<th>Entitlement</th>
<th>Target Group</th>
<th>Implementing Agency</th>
<th>Special features</th>
</tr>
</thead>
<tbody>
<tr>
<td>26</td>
<td>Chief Minister’s Relief Fund</td>
<td>Since 1954</td>
<td>A lump sum amount of Rs. 10,000/-</td>
<td>15. needy and indigent persons.</td>
<td>Orissa State govt</td>
<td>The Orissa Chief Minister’s Relief Fund was created with a view to providing financial assistance to needy and indigent persons for their treatment from major ailments like cancer, cardiac surgery and kidney transplant etc. Financial assistance is also provided to the distressed people affected by major calamities like flood, cyclone, drought and fire accidents of devastating nature. Only applications of indigent persons with annual income not exceeding Rs. 25,000 in rural areas and Rs. 35,000 for urban areas are considered. Although there is no mention of HIV in the eligibility criteria in the official website for this scheme, women participants have benefitted from CM’s relief fund after the death of their spouse. Women were required to submit photocopies of the ICTC report, copy of the voter ID card, income certificate, proof of residence address and the death certificate of the deceased spouse to avail the CMs fund.</td>
</tr>
</tbody>
</table>
## Social Protection Schemes in India – Data on funds allocation, funds utilised and number of beneficiaries

### 2009-2010

<table>
<thead>
<tr>
<th>Type of scheme and States</th>
<th>Funds allotted</th>
<th>Funds spent</th>
<th>Total number of beneficiaries</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>National Social Assistance Programme (NSAP)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indira Gandhi National Widow Pension (IGNWPS)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gujarat</td>
<td>7262.00 (lacs)*</td>
<td>6438.00 (lacs)*</td>
<td>1,28,983</td>
</tr>
<tr>
<td>Orissa</td>
<td>22043.00 (lacs)*</td>
<td>13596.05 (lacs)*</td>
<td>3,06,923</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>15259.00 (lacs)*</td>
<td>12788.30 (lacs)*</td>
<td>1,55,409</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>28618.00 (lacs)*</td>
<td>20986.26 (lacs)*</td>
<td>3,57,014</td>
</tr>
<tr>
<td><strong>Indira Gandhi National Old Age Pension Scheme (IGNOAPS)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gujarat</td>
<td>7262.00 (lacs)*</td>
<td>6438.00 (lacs)*</td>
<td>2,687</td>
</tr>
<tr>
<td>Orissa</td>
<td>22043.00 (lacs)*</td>
<td>13596.05 (lacs)*</td>
<td>28,053</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>15259.00 (lacs)*</td>
<td>12788.30 (lacs)*</td>
<td>1,59,292</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>28618.00 (lacs)*</td>
<td>20986.26 (lacs)*</td>
<td>18,879</td>
</tr>
<tr>
<td><strong>Targeted Public Distribution System</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gujarat</td>
<td>NA</td>
<td>NA</td>
<td>8.098 (lacs) AAY families identified &amp; RC issued</td>
</tr>
<tr>
<td>Orissa</td>
<td>NA</td>
<td>NA</td>
<td>12.645 (lacs) AAY families identified &amp; RC issued</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>NA</td>
<td>NA</td>
<td>9.321 (lacs) AAY families identified &amp; RC issued</td>
</tr>
</tbody>
</table>

1 Annexure II: National social Assistance Programme and Annapurna in Agenda Items for the Performance Review Committee (PRC) Meeting to be held on 13th April 2010. Available online at: http://rural.nic.in/latest/NSAP_PRC_Agenda_06042010.pdf

2 Annexure V: State-wise estiamted and Actual coverage under Widow and Disability Pension Scheme (2009-10) in Agenda Items for the Performance Review Committee (PRC) Meeting to be held on 13th April 2010. Available online at: http://rural.nic.in/latest/NSAP_PRC_Agenda_06042010.pdf

3 Annexure III: Approved number and coverage of beneficiaries under IGNAPS in Agenda Items for the Performance Review Committee (PRC) Meeting to be held on 13th April 2010. Available online at: http://rural.nic.in/latest/NSAP_PRC_Agenda_06042010.pdf

<table>
<thead>
<tr>
<th>Tamil Nadu</th>
<th>NA</th>
<th>NA</th>
<th>18.646(lacs) AAY families identified &amp; RC issued</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ICDS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gujarat</td>
<td>16491.86 lacs</td>
<td>15596.07 lacs</td>
<td>NA</td>
</tr>
<tr>
<td>Orissa</td>
<td>16934.58 lacs</td>
<td>18081.79 lacs</td>
<td>NA</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>19486.76 lacs</td>
<td>20226.22 lacs</td>
<td>NA</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>18163.08 lacs</td>
<td>17203.97 lacs</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Mid Day Meal Scheme</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gujarat</td>
<td>NA</td>
<td>NA</td>
<td>386492</td>
</tr>
<tr>
<td>Orissa</td>
<td>50719.42 lacs</td>
<td>10312.55 lacs</td>
<td>6467059</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>20000.00 lacs</td>
<td>15214.87 lacs</td>
<td>8071477</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>23053.34 lacs</td>
<td>14318.98 lacs</td>
<td>5022030</td>
</tr>
<tr>
<td><strong>Mahatma Gandhi National Rural Employment Guarantee Act (MGNREGA)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gujarat</td>
<td>631.10 crores</td>
<td>444.96 crores</td>
<td>1279789 ( no of households provided employment)</td>
</tr>
<tr>
<td>Orissa</td>
<td>670.57 crores</td>
<td>421.84 crores</td>
<td>787276</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>6927.03 crores</td>
<td>4884.46 crores</td>
<td>6006265</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>2167.99 crores</td>
<td>1308.51 crores</td>
<td>3288263</td>
</tr>
<tr>
<td><strong>Swarnajayanti Gram Swarozgar Yojana (SGSY)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gujarat</td>
<td>2298.16 lacs</td>
<td>2067.32 lacs</td>
<td>NA</td>
</tr>
<tr>
<td>Orissa</td>
<td>6226.50 lacs</td>
<td>1316.63 lacs</td>
<td>NA</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>3121.50 lacs</td>
<td>1446.09 lacs</td>
<td>NA</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>4813.50 lacs</td>
<td>4440.03 lacs</td>
<td>NA</td>
</tr>
</tbody>
</table>

**Notes:**

- Ministry of Housing & Urban Poverty Alleviation
<table>
<thead>
<tr>
<th>State</th>
<th>Population (lacs)</th>
<th>Coverage (NA)</th>
<th>Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gujarat</td>
<td>1501.44</td>
<td>NA</td>
<td>649</td>
</tr>
<tr>
<td>Orissa</td>
<td>1476.59</td>
<td>NA</td>
<td>2678</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>2623.52</td>
<td>NA</td>
<td>667</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>3817.38</td>
<td>NA</td>
<td>NA</td>
</tr>
</tbody>
</table>

**National Family Benefit Scheme**

<table>
<thead>
<tr>
<th>State</th>
<th>Coverage (NA)</th>
<th>Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gujarat</td>
<td>NA</td>
<td>9506</td>
</tr>
<tr>
<td>Orissa</td>
<td>NA</td>
<td>16418</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>NA</td>
<td>15170</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>NA</td>
<td>13898</td>
</tr>
</tbody>
</table>

*NA – Not Available

*Scheme wise figures not available. Data indicative of NSAP which includes schemes like IGNWPS, IGNOAPS, NFBS, NDPS and Annapurna

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*Annexure IV: NFBS: Coverage and Estimated Numbers in Agenda Items for the Performance Review Committee (PRC) Meeting to be held on 13th April 2010. Available online at: [http://rural.nic.in/latest/NSAP_PRC_Agenda_06042010.pdf](http://rural.nic.in/latest/NSAP_PRC_Agenda_06042010.pdf)*
STEP 1
Gramsabha will select you as a beneficiary.

STEP 2
You will receive an application from the Gramsevak.

STEP 3
Your application will be forwarded to the TDO by the Gramsevak.

STEP 4
TDO will sanction your application and issue a letter to you.

STEP 5
You will receive an advance of Rs. 5000/-

STEP 6
You will receive the remaining installments as per the progress of the house.

Source: Commissionerate of Rural Development, Gujarat state (http://www.ruraldev.gujarat.gov.in/iay.htm)
## Key Informant Interview Schedule

**Study on social protection schemes for PLHIV**
*(Semi structured interview schedule for Key Informants)*

Number:_________

### IDENTIFICATION DATA

1. State:______________________

1.1 District: ______________________

1.3 Organisation: __________________________________

1.4 Address: __________________________________

1.5 Designation : ______________________

1.6 Qualification: ______________________

1.7 Experience in the current position: ______________________

1.8 Sex of the Respondent: Male ………………………Female………….…………Other …………..………….

### STARTING DATE OF INTERVIEW

INTERVIEW BEGINS AT __________ AM/PM

### ENDING DATE OF INTERVIEW

INTERVIEW ENDS AT __________ AM/PM

Result code of interview:

1. Completed
2. Partly completed
3. Refused
4. Not found in particular centre
5. Left the job
6. Other ______________________

(Specify)
2. **Perception about need of social protection schemes for PLHIV**

2.1. Are you aware of social protection schemes for PLHIVs? If yes, can you specify.

2.2. Apart from the above, do you know of any other social protections schemes that can benefit PLHIVs also?

2.3. Why do you think PLHIVs need social protection schemes?

2.4. Apart from PLHIVs, other people like widows, old persons and poor households also need social protection. Do you think PLHIVs have special needs apart from other people? If yes, what are those special needs?

2.5. What kind of social protection schemes do PLHIVs need?

- Travel concession for ART Treatment
- Nutrition
- Pension schemes
- Health Insurance
- Livelihood
- Housing schemes
- Direct financial help
- Legal aid
- Any other

3. **Efforts and experiences of the CBOs/NGOs in reaching the social protection schemes to PLHIVs and the affected families.**

3.1 Does your organisation do any work related to social protection of PLHIVs? If yes, please specify.

3.2 Is your organisation working on reaching government’s social protection schemes to PLHIVs? How does it do so?

3.3 Is your organisation focussing on any of the following social protection schemes in its work? *(Note to interviewer – if the answer is yes for any scheme, take the details along the lines of experience, procedural issues, ease of use, adequate or inadequate, appropriate or inappropriate and advantages or disadvantages)*

- Travel concession for ART treatment
- ICDS
- Getting BPL cards
- PDS
- Annapoorna Yojana
- Antodaya Anna Yojana
- Mid-day meal scheme
- SGSY
- SJSRY
- NREGS
- Widow pension scheme
- Old age pension scheme
- Janani Suraksha Yojana
- Family benefit scheme
- Indira Awaas Yojana
- Private health insurance like Star Insurance
- Legal Aid
- Any other
4. **Experiences of using the schemes**

4.1 What is your opinion about your organisation’s work on social protection schemes?

4.2 Do you know of any other schemes that you are not working on right now but could be useful to try?

4.3 What are the factors that help to reach the schemes to PLHIVs?

4.4 What are the main factors that make it difficult for PLHIVs to reach the scheme?

5. **Challenges**

5.1 What challenges do you face in reaching the social protection schemes to PLHIVs?

5.2 How do you or can you overcome those challenges?

5.3 Can you describe one example?

5.4 What are the confidentiality issues in getting the schemes?

5.5 What are the issues related to disclosure in getting the schemes?

5.6 What are the issues related to stigma and discrimination when using these schemes?

5.7 Have there been experiences related to harassment while using the schemes? If yes, please describe.

6. **Perception on Targeting and Mainstreaming**

6.1 What are the advantages of making special schemes only for the benefit of PLHIV and HIV affected households?

6.2 Probe: does it lead to any form of stigma, discrimination or isolation of any groups or individuals?

6.3 What would be the advantages of including PLHIVs in these existing social protection schemes?

6.4 What would be the disadvantages of including PLHIVs in these existing social protection schemes?

7. **Gender Dimensions**

7.1 What are the gender dimensions of providing social protection for HIV/AIDS affected households? (Are there any differences between men and women while reaching or getting the benefits of social protection schemes for PLHIVs and HIV affected households?)

7.2 Is gender disaggregated data available on the utilisation of the schemes in your organisation?

    Yes ______ No ______

7.3 Probe: Who among men or women is using these schemes more?

7.4 Which schemes and why?

7.5 Are men getting more advantage than women in any of the schemes? If yes, why?

7.6 Are women getting more advantage than men in any of the schemes? If yes, why?

7.7 Do households show preference for men or women in reaching/utilising these schemes?

7.8 What are the specific challenges for getting the schemes for women? (Note to interviewer: ask this question if answer not received so far)

7.9 Probe: are men more reluctant than women to use certain schemes and why?
7.10 Probe: are women more reluctant than men to use certain schemes and why?
7.11 Do women or men face more procedural delays while using any of the schemes based on gender? If yes, why?
7.12 Do women or men face more stigma and discrimination while using any of the schemes based on gender? If yes, why?
7.13 Which existing social protection schemes are more relevant/applicable to women living with or affected by HIV? (Note to interviewer: explore for women in varied situations like single/married women, women headed households, abandoned women, etc.)
7.14 In what ways could the schemes be made easier to reach/use for women?

8 Suggestions
8.1 How can the social protection schemes be made more popular among PLHIVs?
8.2 How can the social protection schemes be made more reachable to PLHIVs and the affected households?
8.3 How can the social protection schemes be made more beneficial for PLHIVs/affected households?
8.4 What changes need to be made for getting the maximum benefit for men out of the schemes?
8.5 What changes need to be made for getting the maximum benefit for women out of the schemes?
8.6 In many cases, elderly people or other families-members or community members look after the children (orphans) after their parents have died of AIDS. Which schemes are most effective for such people?
8.7 If we have to prioritise few schemes for PLHIV and the affected households which ones will you suggest?
8.8 If the benefits of several different schemes are put together, it will result in a collective amount so that an affected family can manage poverty. What is your opinion about putting together different schemes to get a collective amount?
8.9 What are your suggestions for promoting social protection measures for PLHIVs and HIV/AIDS-affected households? (Note to interviewer: go into details of every answer to get micro-planning steps and probe for creative solutions)
8.10 Do you have any other suggestions for promoting social protection measures for PLHIVs and HIV/AIDS-affected households?
8.11 Do you have any specific suggestions regarding following schemes:
   - Travel concession for ART treatment.
   - ICDS:
   - Getting BPL cards:
   - Do you think that all PLHIVs irrespective of their economical condition should get benefits of the BPL schemes? Why?
   - PDS:
   - Annapurna Yojana:
   - Antodaya Anna Yojana:
   - Mid-day meal scheme:
   - SGSY:
   - SJSRY:
   - NREGS:
- Widow pension schemes:
- Old age pension scheme:
- Janani suraksha yojana:
- Family benefit scheme:
- Indira Awaas Yojana:
- Private health insurance like Star health insurance
- Legal aid:
- Any other:
FGD Guideline for Users

Brief introduction
A PLHIV and his/her family may feel different levels of impact of HIV and AIDS. These include increased spending on health and hospitalization depending on the stage of the illness. Impact may also be there in the form of loss of earnings due to severe illness or death. Women may feel the dual burden of care-giving as well as earning money. Children and youth in the family may feel forced to leave school and earn money. Households that are poor may sell their house, land, livestock or other assets to cope with these impacts. In these circumstances, poorer households feel greater impact of AIDS than richer households. Social protection in the form health or life insurance, pension schemes, nutritional support or direct financial benefit helps poor households cope with these impacts. The government of India has several social protection schemes like ICDS, PDS, MDM, Annapurna Yojana, Antodaya Anna Yojana, SGSY, NREGS, Janani Suraksha Yojana, Widow pension and so on to help the poor households cope with poverty. In this study, we want to understand whether PLHIVs are using such schemes? If yes, what are the experiences and if you what are reasons for the same?

Themes and Questions
1. Awareness and use of the Schemes
   1.1 Can each of you say what social protection schemes are you availing or have availed of in the past?
   1.2 Have you availed of any of the following schemes?
      • Travel concession for ART treatment:
      • ICDS:
      • Getting BPL cards:
      • PDS:
      • Annapurna Yojana:
      • Antodaya Anna Yojana:
      • Mid-day meal scheme
      • SGSY
      • SISRY:
      • NREGS:
      • Widow pension schemes:
      • Old age pension scheme:
      • Janani suraksha Yojana:
      • Family Benefit scheme:
      • Indira Awaas Yojana:
      • Private health insurance like Star health insurance:
      • Legal aid:
      • Any other:
1.1. What is the eligibility for availing these schemes? (ask for each of the schemes used by the participants)
1.2. What kind of benefit/entitlement did you get from it (monetary and otherwise) from each of the schemes you availed?
1.3. How was the benefit received? (Cheque / cash, at home, in the bank, at the office, by post)
1.4. Was the benefit substantial?
1.5. Are you satisfied with the benefits from the schemes? Why?
1.6. Are you dissatisfied with the benefits from the schemes? Why?
1.7. How much time lapse was there between application and actual receipt of the benefit? Why?

2. Source of information
2.1. How did you get to know about the scheme?

3. Assistance in accessing the scheme
3.1. Who assisted you in accessing the scheme? and how?
3.2. What procedure did you follow to access the same? What paperwork or procedures did you adhere to?
3.3. How did you find the procedures?

4. Experiences of accessing the schemes (challenges and facilitating factors)
4.1. Can you describe your experience of accessing the schemes?
4.2. For people who had difficulties in accessing the schemes—ask What were the main barriers in accessing the scheme?
4.3. How did you overcome the difficulties you expressed above?
4.4. What helped you the most in accessing the scheme and getting benefits?
4.5. What were the other facilitating factors?

5. Issues related to HIV status
5.1. Were there any confidentiality issues while accessing any of the schemes?
5.2. Were there any issues related to disclosure while accessing any of the schemes?
5.3. Did you experience any S and D while accessing the scheme? If yes, describe the experience?
5.4. Have there been experiences related to harassment while using the schemes? If yes, please describe.

6. Perception about need of social protection schemes for PLHIV
6.1. Apart from PLHIVs, other people like widows, old persons and poor households also need social protection. Do you think PLHIVs have special needs apart from other people? If yes, what are those special needs?
6.2. Why do you think PLHIVs need social protection schemes? What do you think are the advantages of the scheme?
6.3. What are the priority needs of PLHIV and affected families? (Probe for 3 main needs)
6.4. What are the main expense heads for PLHIV or affected families as per the stage of the illness?
6.5. What should be the minimum collective amount needed for PLHIV to sustain in the poverty situation?
6.6. What kind of social protection schemes do PLHIVs need?
   ● Travel concession
A Four State Utilization Study

• Nutrition
• Pension schemes
• Health Insurance
• Livelihood
• Housing schemes
• Direct financial help
• Legal aid
• Any other

8.8 If we have to prioritise few schemes for PLHIV and the affected households which ones will you suggest?

7. Perceptions on Targeting and Mainstreaming

7.1 What are the advantages of making special schemes only for the benefit of PLHIV and HIV affected households?
   Probe: does it lead to any form of stigma, discrimination or isolation of any groups or individuals?

7.2 What would be the advantages of including PLHIVs in these existing social protections schemes?

7.3 What would be the disadvantages of including PLHIVs in these existing social protection schemes?

8 Gender Aspect

8.1 Which existing social protection schemes are more relevant/applicable to women living with or affected by HIV? (Note to interviewer: explore for women in varied situations like single/married women, women headed households, abandoned women, etc.)

8.2 Which existing social protection schemes are more relevant/applicable to men living with or affected by HIV? (Note to interviewer: explore for msm, transgender, situations like single/married men, etc.)

8.3 Are men more reluctant than women to use certain schemes and why?

8.4 Do women face any challenges for accessing the schemes different from that of men? Why?

8.5 Do women/men face more procedural delays or more Stigma and Discrimination in accessing any of the schemes? Why?

8.6 Do women have any experiences of harassment when accessing the scheme?

8.7 Do women or men face more stigma and discrimination while using any of the schemes based on gender? If yes, why?

9. Suggestions on accessibility and maximising benefits

9.1 How can the social protection schemes be made more reachable to PLHIVs and the affected households OR What can be done to remove the barriers to access?

9.2 How can the social protection schemes be made more popular to PLHIVs and the affected households?

9.3 What changes need to be made for getting the maximum benefit for men out of the schemes?

9.4 What changes need to be made for getting the maximum benefit for women out of the schemes?

9.5 In many cases, elderly people or other families members or community members
look after the children (orphans) after their parents have died of AIDS. Which schemes are most effective for such people?

9.6 If the benefits of several different schemes are put together, it will result in a collective amount so that an affected family can manage poverty. What is your opinion about putting together different schemes to get a collective amount?

9.7 What are your suggestions for promoting social protection measures for PLHIVs and HIV/AIDS-affected households? (Note to interviewer: go into details of every answer to get micro-planning steps and probe for creative solutions)

9.8 What actions can be taken by
- Govt.
- Individual
- Community (PLHIV Network)
- NGO

9.9 Do you have any other suggestions for promoting social protection measures for PLHIVs and HIV/AIDS-affected households?

10. Do you have any specific suggestions regarding following schemes:

10.1. Travel concession for ART treatment:
10.2. ICDS:
10.3. Getting BPL cards:
10.4. Do you think that all PLHIVs irrespective of their economical condition should get benefits of the BPL schemes? Why?
10.5. PDS:
10.6. Annapurna Yojana:
10.7. Antodaya Anna Yojana:
10.8. Mid-day meal scheme:
10.9. SGSY:
10.10. SJRY:
10.11. NREGS:
10.12. Widow pension schemes:
10.13. Old age pension scheme:
10.14. Janani suraksha Yojana:
10.15. Family Benefit scheme:
10.16. Indira Awaas Yojana:
10.17. Private health insurance like Star health insurance:
10.18. Legal aid:
10.19. Any other:
FGD Guideline for Non-Users

Brief introduction
A PLHIV and his/her family may feel different levels of impact of HIV and AIDS. These include increased spending on health and hospitalization depending on the stage of the illness. Impact may also be there in the form of loss of earnings due to severe illness or death. Women may feel the dual burden of care-giving as well as earning money. Children and youth in the family may feel forced to leave school and earn money. Households that are poor may sell their house, land, livestock or other assets to cope with these impacts. In these circumstances, poorer households feel greater impact of AIDS than richer households. Social protection in the form health or life insurance, pension schemes, nutritional support or direct financial benefit helps poor households cope with these impacts. The government of India has several social protection schemes like ICDS, PDS, MDM, Janani Suraksha Yojana, Widow pension and so on to help the poor households cope with poverty. In this study, we want to understand whether PLHIVs are using such schemes? If yes, what are the experiences and if you what are reasons for the same

Themes and Questions
1. Awareness of the schemes
   1.1 Have you heard of any of the social protection schemes relevant to PLHIV?
      Yes_____ No_____
   1.2 If yes, which are the schemes you have heard of?
   3.3 What is the eligibility for these schemes? (ask for each of the schemes used by the participants)
   3.4 Are you aware of the benefit/entitlements from the schemes (monetary and otherwise)?
2. Reason for not availing any of the schemes
   1.1 What are the reasons for not availing any of these schemes?
   2.2 Were there any confidentiality issues while accessing any of the schemes?
   4.1 Were there any issues related to disclosure while accessing any of the schemes?
   4.2 Did you experience any Stigma and Discrimination while accessing the scheme?
      If yes, describe the experience?
3. If they made efforts and failed to access
   3.1 Can you describe your experience of accessing the schemes?
   3.2 Why did it not work?
   3.3 What were the main hindrances in accessing the scheme and/ getting benefits?
   3.4 What were the other obstructing factors?
4. Assistance in accessing the scheme
   4.1 Do you need any assistance in accessing the schemes?
   4.2 Who do you think can assist you? and How?
5 Perception about need of social protection schemes for PLHIV

5.1 Apart from PLHIVs, other people like widows, old persons and poor households also need social protection. Do you think PLHIVs have special needs apart from other people? If yes, what are those special needs?

5.2 Why do you think PLHIVs need social protection schemes?

5.3 What are the priority needs of PLHIV and affected families? (Probe for 3 main needs)
   5.3.1 What are the main expense heads for PLHIV or affected families as per the stage of the illness?
   5.3.2 What should be the minimum collective amount needed for PLHIV to sustain in the poverty situation?

5.4 What kind of social protection schemes do PLHIVs need?
   5.4.1 Travel concession for ART Treatment
   5.4.2 Nutrition
   5.4.3 Pension schemes
   5.4.4 Health Insurance
   5.4.5 Livelihood
   5.4.6 Housing schemes
   5.4.7 Direct financial help
   5.4.8 Legal aid
   5.4.9 Any other

5.5 If we have to prioritise few schemes for PLHIVs and the affected households which ones will you suggest?

6 Perceptions on Targeting and Mainstreaming

6.1 What are the advantages of making special schemes only for the benefit of PLHIV and HIV affected households?

6.2 Probe: does it lead to any form of stigma, discrimination or isolation of any groups or individuals?

6.3 What would be the advantages of including PLHIVs in these existing social protections schemes?

7 Gender Aspect

7.1 Which existing social protection schemes are more relevant/applicable to women living with or affected by HIV? (Note to interviewer: explore for women in varied situations like single/married women, women headed households, abandoned women, etc.)

7.2 Which existing social protection schemes are more relevant/applicable to women living with or affected by HIV? (Note to interviewer: explore for women in varied situations like single/married women, women headed households, abandoned women, etc.)

7.3 Which existing social protection schemes are more relevant/applicable to men living with or affected by HIV? (Note to interviewer: explore for msm, transgender, situations like single/married men, etc.)

7.4 Are men more reluctant than women to use certain schemes and why?

7.5 Are there any specific reasons why women don’t want to or cannot access any of these schemes?

7.6 Do women/men face more procedural delays in accessing any of the schemes? Why?
7.7 Do women or men face more stigma and discrimination while using any of the schemes based on gender? If yes, why?

8 Suggestions on accessibility and maximizing benefits

8.1 How can the social protection schemes be made more reachable to PLHIVs and the affected households? OR What can be done to remove the barriers to access?

8.2 What are the gender dimensions of providing social protection for HIV/AIDS affected households? (Are there any differences between men and women while reaching or getting the benefits of social protection schemes for PLHIVs and HIV affected households?)

8.3 What changes need to be made for getting the maximum benefit for men out of the schemes?

8.4 What changes need to be made for getting the maximum benefit for women out of the schemes?

8.5 In many cases, elderly people or other family members or community members look after the children (orphans) after their parents have died of AIDS. Which schemes are most effective for such people?

8.6 If the benefits of several different schemes are put together, it will result in a collective amount so that an affected family can manage poverty. What is your opinion about putting together different schemes to get a collective amount?

8.7 What are your suggestions for promoting social protection measures for PLHIVs and HIV/AIDS-affected households? (Note to interviewer: go into details of every answer to get micro-planning steps and probe for creative solutions)

8.8 What actions can be taken by

8.8.1 Government

8.8.2 Individual

8.8.3 Community (PLHIV Network)

8.8.4 NGOs

8.9 Do you have any other suggestions for promoting social protection measures for PLHIVs and HIV/AIDS-affected households?

8.10 Do you have any specific suggestions regarding following schemes:

8.10.1 Travel concession for ART treatment.

8.10.2 ICDS:

8.10.3 Getting BPL cards:

8.10.3.1 Do you think that all PLHIVs irrespective of their economical condition should get benefits of the BPL schemes? Why?

8.10.4 PDS:

8.10.5 Annapurna Yojana:

8.10.6 Antodaya Anna Yojana:

8.10.7 Mid-day meal scheme:

8.10.8 SGSY:

8.10.9 SJSRY:

8.10.10 NREGS:

8.10.11 Widow pension schemes:

8.10.12 Old age pension scheme:

8.10.13 Janani suraksha yojana:
8.10.14. Family benefit scheme:
8.10.15. Indira Awaas Yojana:
8.10.16. Private health insurance like Star health insurance:
8.10.17. Legal aid:
8.10.18. Any other:
RESERCH PARTICIPANT CONSENT FORM
(In Depth Interview)

Research on Rapid assessment of the Social Protection Schemes for PLHIV in the selected states

Purpose of Research
I understand that the purpose of this research is to explore the existing mechanisms for accessing social Protection Schemes relevant to PLHIV and documenting experiences of members of Positive Networks, CBOs and NGOs and to seek my suggestions on how the mechanisms can be improved and what would be the best way to meet the needs of PLHIV and HIV/ AIDS through the social protection schemes of the government and other NGOs and Stakeholders. I understand that this information will be presented to the UNDP stakeholders and NACO to help those responsible make decisions about improving the mainstreaming of the social protection schemes for PLHIV.

Specific Procedures to be Used
I understand that the researchers will conduct an in-depth interview. The interview will take place between August and September 2010.

Duration of Participation
I understand that I will be asked to participate in the interview, which will last approximately 1½ to 2 hours.

Benefits to the Individual
By participating in this interview, I am aware of the benefits. By participating in this research, I will have the opportunity to share my experiences related to accessing social protection schemes for PLHIV and to voice my views and perspectives on successful ways to strengthen the mainstreaming of the existing social protection schemes. However, I am aware that participation does not entail any direct benefit for me.

Risks to the Individual
I understand that by participating in this research I may be asked to voice some of my personal experiences that may have been frustrating or upsetting to me. I understand that this research may cause some discomfort or distress for me. However, I do understand that the risk involved is no greater than that encountered in daily activities.
Confidentiality
I agree/ don’t agree to my interview being audio recorded. I am aware that the audio recording is done to facilitate the accuracy and for the ease of documentation. The recording tapes will not be used for any other purpose.

I understand that what I say in the interview will be kept confidential. My name will not be shared with anyone outside of the research team, and my responses will not be connected to my name in any way. The only form that will include my name is this consent form, which will be kept separate from the discussion notes/ recording tapes and stored in a locked filing cabinet.

Voluntary Nature of Participation
I do not have to participate in this research project. If I agree to participate I can withdraw my participation at any time without penalty.

Human Subject Statement:
If I have any questions about this research project, I can contact Dr. Vimla Nadkami (vimla@tiss.edu)

Participant’s initials _____________________________

Date _________________________

I HAVE HAD THE OPPORTUNITY TO READ AND UNDERSTAND THIS CONSENT FORM, ASK QUESTIONS ABOUT THE RESEARCH PROJECT AND AM PREPARED TO PARTICIPATE IN THIS PROJECT.

_________________________________________ __________  ____________________________
Participant’s Signature                             Date              Participant’s Name

_________________________________________ ____________________________
Researcher’s Signature                             Date